

Communication in Medical Interactions: Perspectives of Individuals with
Communication Disorders, Their Caregivers, and Physicians

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Abstract

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Introduction: Individuals with communication disorders form a vulnerable patient population in health care. Their problems with communication in medical interactions can lead to higher rates of medical errors, reduced accessibility to health care, and decreased satisfaction with services when compared with the average patient population. Communication Accommodation Theory (CAT) has recently been used in research to explain communication during medical interactions involving patients with communication disorders. However, this research focuses on dyadic medical interactions between patients and physicians, failing to consider the potential effects that caregivers can have on these interactions. The purpose of this study was to explore the experiences and perspectives of patients with communication disorders, their family caregivers, and physicians related to communication during medical interactions. In

addition, this study examines the feasibility of CAT to help explain and predict communication during these medical interactions.

Methods: A total of 18 individuals - six patients with a primary communication disorder diagnosis of aphasia, six family caregivers, and six practicing physicians - participated in semi-structured, face-to-face interviews. Participants were asked about their experiences with communication during triadic medical interactions. Interviews were audio and/or video recorded and then transcribed. Transcripts were coded and a thematic analysis was conducted.

Results: While patients and caregivers generally described their communication experiences as positive, all participants discussed challenges and frustrations they experienced when communicating during medical interactions. Three themes emerged from participants' experiences and perspectives: 1) patients and caregivers work as a team, 2) patients and caregivers want physicians to "just try" to communicate with the patient, and 3) physicians want to try to communicate with the patient, but may not know how. Patients and caregivers provided advice to help physicians improve their communication, and physicians suggested content areas to include in future communication skills training for medical students and practicing physicians.

Discussion: Results of this study suggested that although the participants' experiences were generally positive, the perspectives of patients and caregivers regarding communication during medical interactions seemed to be somewhat misaligned with those of physicians. Patients and caregivers discussed how some physicians seemed to be either unaware when patients were struggling to communicate, or did not to change their communication style to help patients. Physicians, on the other hand, seemed to acknowledge the importance of changing how they communicate to make accommodations for these patients, but discussed not having the education

and training to know how. Results of this study also provided support for the use of CAT to represent communication during these medical interactions, and a working model of CAT is proposed. Participants frequently discussed the need for successful accommodation, or changing the way one communicates, during medical interactions to help facilitate the patients' increased understanding and ability to express themselves. However, over- and under-accommodation were commonly reported instead. Finally, results of this study highlighted the importance of speech-language pathologists (SLPs) in helping to improve communication during medical interactions involving patients with communication disorders. Implications for future research and clinical practice for physicians and SLPs are also discussed.

Plain Language Summary

Good communication between patients and doctors is important. People who struggle to communicate often have difficulty getting good health care. Poor communication between patients and doctors can lead to problems for patients, including: more medical errors and health problems, less satisfaction with health care with more switching of doctors. Poor communication with patients can also cause burnout and frustration for doctors.

We interviewed patients with communication problems, their family caregivers who are often with them during medical visits, and doctors. We recorded and transcribed the interviews to learn about their experiences trying to communicate with each other during medical visits. We also wanted to find out if Communication Accommodation Theory (CAT) could be a useful framework to describe how communication works during medical visits.

We learned the following from this study:

1. Even though peoples' experiences with communication during medical visits were mostly positive, communication can be challenging for everyone involved.
2. Patients who have difficulty communicating and their caregivers seem to work together and function as a communication team.
3. Patients and caregivers felt doctors should do more to try and help when patients are struggling to communicate.
4. Doctors talked about wanting to help when patients struggle, but often did not know what to do because they had not been trained in how to improve communication in patients with communication problems.

We also learned that CAT seems to be a good framework to describe how communication works during these medical visits, and were able to develop a model of CAT to help explain how communication works during these types of visits. Results of this study also showed us that providing training to doctors to teach them how to help when patients struggle to communicate is important. Perhaps CAT can be used to design and implement this communication training. Finally, results of this study suggested that speech-language pathologists, who specialize in helping to improve communication, may be ideal in delivering this training.

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DEDICATION

To the patients who strive to be heard, to their caregivers who strive to help,

And to the physicians who strive to provide the best care possible.

*"The basic building block of good communication is the feeling that every human being is unique
and of value." -Unknown*

CHAPTER ONE: INTRODUCTION

Communication in Medical Interactions

Individuals with communication disorders form a vulnerable patient population in health care (Hemsley, Balandin, & Togher, 2008a; Kagan & LeBlanc, 2002; Law, Bunning, Byng, Farrelly, & Heyman, 2005; Nordehn, Meredith, & Bye, 2006; Patak, Gawlinski, Fung, Doering, & Berg, 2004). The presence of communication disorders has been linked to higher rates of medical errors (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008), reduced accessibility to health care (Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004), and decreased satisfaction with services provided when compared with the average patient population (Hemsley, Werninck, & Worrall, 2013; Hoffman et al., 2005). Patients with communication disorders routinely experience diminished autonomy in making health-related decisions, as well as decreased opportunities to participate in shared decision-making about their care (Murphy, 2006; Pound, Duchan, Penman, Hewitt, & Parr, 2007). Communication breakdowns, or problems with communication, that often occur during medical interactions with physicians often create increased vulnerability for these patients.

Importance of Effective Communication in Medical Interactions

Communication in patient-centered care. In the current health care climate, considerable emphasis is being placed on patient-centered care (Baile et al., 2000; Cunningham & Ward, 2003; Duggan, 2006; Ziviani et al., 2004). Patient-centered care involves health care providers recognizing the needs, beliefs, and perspectives of each patient, and focuses on patients taking a more active role in decisions related to their medical care (Mead & Bower, 2000). Communication between patients and their physicians during medical interactions is

consequently at the heart of patient-centered care. Because communication is the “medium” through which health care is provided (Lipkin, 2010, p. 3), effective patient-provider communication during these interactions is often considered key to successfully achieving patient-centered care.

Effective patient-provider communication involves a successful balance of establishing and maintaining rapport and trust, exchanging information, and sharing in the decision-making process (Rayner & Marshall, 2003). It includes physicians being a source of information for patients, and guiding them to make fully-informed decisions about their care. Effective patient-provider communication also involves physicians promoting their patients’ self-efficacy skills related to managing their health (Allen, Iezzoni, Huang, Huang, & Leveille, 2008), and integrating complex medical issues with patient-centered values (Back et al., 2007).

Communication and patient outcomes. For this study, medical interactions were defined as any communication exchanges that occur between patients and their physicians. While face-to-face conversations between patients and physicians are the most common type of medical interaction, and often the most relevant when exploring the effectiveness of patient-provider communication, patients may also communicate with physicians in other ways such as over the phone or through email. These exchanges were also considered types of medical interactions for this study.

Research has linked effective patient-provider communication during medical interactions to a range of positive patient outcomes including increased adherence to treatment recommendations, satisfaction with services, and improved overall health (Egnew, Mauksch, Greer, & Farber, 2004; Fallowfield et al., 2002). Poor communication between physicians and

patients during these interactions has been shown to negatively impact patients' understanding of their diagnoses and treatment options, to diminish patients' adherence to treatment recommendations, and to contribute to more frequent switching of physicians (Baile et al., 2000; Kennedy Sheldon, 2005). Ineffective patient-provider communication can also result in increased health care costs, more malpractice claims filed against physicians, and higher stress levels in physicians that can potentially lead to decreased job satisfaction and burnout (Mauksch, Dugdale, Dodson, & Epstein, 2008; Tulsky, 2005).

Changes in communication skills training. The importance of effective patient-provider communication in ensuring health care quality and accessibility has recently gained recognition from various organizations. The Accreditation Council on Graduate Medical Education, the Association of American Medical Colleges, and the Institutes of Medicine have issued requirements to include training in effective patient-provider communication in medical school curricula (Brunett et al., 2001; Duggan, 2006; Egnew et al., 2004; Losh et al., 2005). Health care organizations and third party payers, such as Medicare, have also begun using reports of patient satisfaction with physicians' communication skills during medical interactions as a basis for compensation and referrals for communication skills training programs (Duffy, Gordon, Whelan, Cole-Kelly, & Frankel, 2004; Landro, 2013).

Consequently, most medical schools have recently adjusted their curricula to include some form of training in effective patient-provider communication (Bowyer et al., 2010; Purdy & Hindenlang, 2005; Wright, Sparks, & O'Hair, 2013; Ziviani et al., 2004). In fact, according to a 2013 Wall Street Journal article, some universities have expanded communication skills training programs from years 1 and 2 to across all 4 years of medical school (Landro, 2013). Communication skills training programs typically encourage physicians to listen to their patients,

and teach them how to deliver bad news, promote shared decision-making with patients, and emphasize patient self-efficacy during medical encounters (Baile et al., 2000; Egnew et al., 2004).

Current research supports the effectiveness of patient-provider communication training programs in medical education (Back et al., 2007; Bowyer et al., 2010; Helitzer et al., 2011; Losh et al., 2005; Tulskey, 2005). However, research on communication skills training in medical education rarely explores the perspectives of the individuals involved in medical interactions. These perspectives can be important for improving this training and informing health communication research (Cegala, Coleman, & Turner, 1998). Additionally, communication skills training programs in medical education rarely include information related to facilitating effective patient-provider communication with patients who have communication disorders.

Medical Interactions Involving Patients with Communication Disorders

Barriers for patients with communication disorders. Medical interactions can be daunting for patients with communication disorders. For example, while talking on the telephone is one of the most disliked and anxiety-provoking tasks for these patients, the phone is typically the only way patients can schedule an appointment or ask questions related to their care when they are not face-to-face with their health care provider. In addition, written materials utilized in health care (i.e. consent forms, billing forms, patient education materials) are often too complex for many patients with language disorders such as aphasia or cognitive-communication disorders to comprehend (Hoffmann & Worrall, 2004; Rose, Worrall, & McKenna, 2003). Even navigating through medical facilities can create problems for patients who are unable to understand the signage they encounter. However, medical interactions with physicians seem to

create the most significant obstacles for patients with communication disorders in accessing quality health care and taking part in their own health decisions (McCooey, Toffolo, & Code, 2000; Murphy, 2006; Pound et al., 2007).

Common obstacles these patients experience during medical interactions with physicians include insufficient time, lack of familiarity, and poor awareness. The brief time allotted for many medical interactions is another significant obstacle for patients with communication disorders (Ziviani et al., 2004). These patients often require additional time to ask questions related to their care, as well as to comprehend information from physicians and to formulate responses to their questions. Lack of familiarity between patients with communication disorders and physicians also influences the success of their interactions. During initial medical interactions, physicians may not be familiar with how best to communicate with patients with communication disorders. As physicians' familiarity with patients' speech patterns or preferred communication methods increases, the effectiveness of communication during their medical interactions may also improve. Finally, the level of awareness and exposure physicians possess related to communication disorders and how they impact medical interactions may have a direct effect on patient-provider communication. If a physician is not aware that aphasia can limit a patient's ability to verbally communicate without impacting his or her cognition or intelligence, the physician may assume the patient is incapable of participating in decisions related to medical care. In fact, research has suggested that physicians often underestimate the cognitive function of individuals with communication disorders based on their inability to have a conversation (Fox & Pring, 2005).

Addressing communication challenges during medical interactions. Improving the effectiveness of communication during medical interactions between patients with

communication disorders and their physicians seems to be an important way to target meeting the health care needs of these patients. Medical interactions with physicians are common, highly structured, goal-driven, and predictable. Physicians are taught to follow a systematic, formulaic approach to interactions with their patients. They are taught to accomplish a series of predetermined steps including establishing rapport and setting an agenda for the interaction, exploring the patient's symptoms, developing a diagnosis, establishing a plan of care, and concluding the interaction (Brown, Bylund, Eddington, Gueguen, & Kissane, 2010; Makoul, 2001). These predetermined steps may not change when patients exhibit communication disorders. However, physicians may need to adjust how they interact with these patients in order to accomplish the same steps. For example, while asking a question about medication side effects to a patient with aphasia who struggles to comprehend verbal information, a physician may need to write down key words from that question on a white board to help improve the patient's comprehension of what is being asked. For this reason, investigating the experiences and perspectives of individuals involved in these medical interactions may help provide a better understanding of the effective strategies and tools that have been useful in helping to improve communication during these interactions.

Implementing effective patient-provider communication with patients with speech, language, cognitive, or hearing impairments is not a routine part of physician education. In fact, physicians have reported receiving limited training in communicating with patients with any type of disability (Duggan, Bradshaw, Carroll, Rattigan, & Altman, 2009). While physicians receive a significant amount of training in how to facilitate effective patient-provider communication, this training assumes patients and physicians both possess adequate communication skills. Patients with communication disorders often need their conversation partners to modify how they

communicate to improve the effectiveness of interactions (Hinckley, Douglas, Goff, & Nakano, 2013). If physicians are not well-versed and comfortable with strategies to facilitate communication with these patients, they may systematically exclude patients from the medical decision-making process.

Although limited, there is evidence to support the effectiveness of training health care providers to facilitate improved communication with patients who struggle to communicate. For example, results of a study by Harper and Wadsworth (1992) indicated the effectiveness of a self-study educational program focused on improving the provision of health-related information to individuals with mental retardation in medical and dental settings. Physicians, medical students, nurses and nursing assistants who enrolled in the program reported an improvement in communication skills with these patients, including being more proactive with communication and increased knowledge about mental retardation and how it can affect medical interactions.

In another study by Simmons-Mackie and colleagues (2007), multi-disciplinary teams of health care providers were trained in methods for greater inclusion of patients with aphasia in health care. Three teams, one each from acute care, inpatient rehabilitation, and long-term care settings participated in a 2-day training seminar focused on understanding the communication needs of patients with aphasia and developing goals for changing their respective settings to provide greater accessibility. After the training, the teams were asked to implement their goals with consultation from a speech-language pathologist (SLP). While members of all three teams demonstrated increased knowledge of the needs of patients with aphasia and were able to generate ideas for increasing health care accessibility for these patients, only the long-term care and rehabilitation teams were able to implement changes in their settings. The researchers suggested that there may be unique challenges in implementing health care changes for patients

with communication disorders in different settings and that those strategies and training programs might need to be tailored to health care providers depending on their respective settings.

Research specific to providing communication skills training to physicians regarding patients with communication disorders is also emerging. In a 2005 study, Legg and colleagues trained sixth-year medical residents how to use supported communication techniques such as those described by Kagan and colleagues (2001) with patients who have aphasia. Residents who received the training made significant improvements in their communication with these patients during mock medical interviews. Improvements were noted in the amount of information exchanged and the quality of the interactions as rated by SLPs, the residents, and the individuals with aphasia who served as the standardized patients. A control group of residents who received traditional lecture-based information about aphasia without the hands-on training in supported communication techniques did not make similar gains.

Research is also emerging that investigates the effectiveness of training physicians to facilitate improved communication with patients who exhibit a variety of communication disorders. In 2010, a group of SLPs (including the author of this dissertation) piloted a communication skills training seminar for fourth year medical students in the University of Washington (UW) Medical School (Burns, Baylor, Morris, McNalley, & Yorkston, 2012). This ongoing training seminar, titled, "Patient-Provider Communication for Patients with Communication Disorders (PPC-CD)," focuses on teaching medical students about the types and characteristics of different communication disorders their patients may exhibit, as well as the potential effects these disorders can have on medical interactions. This seminar also teaches medical students some basic communication-enhancing strategies they can implement to help

facilitate communication with these patients, and provides hands-on experience for them to practice implementing these strategies with simulated patients. Initial pilot testing resulted in self-reported improvements in medical students' awareness and confidence regarding facilitating communication with these patients during medical interactions. Students have expressed appreciation for the course, and have indicated that they especially benefitted from the hands-on experiential learning that took place in the seminar.

Greater attention has recently been focused on the vulnerability of patients with communication disorders in accessing health care services. For example, research has focused on identifying the struggles health care providers encounter when communicating with patients with severe communication disorders (Hemsley et al., 2001), and investigating the extent to which various health care provider disciplines are educated and trained to use patient-centered care with these patient across different health care settings (Skinder-Meredith, Bye, Bulthuis, & Schueller, 2007). One study by Parr and colleagues (2006) even worked with people with aphasia to design a communication 'tool-kit' to help health care providers modify how they deliver their services to be more communicatively accessible for these patients. In 2010, the Joint Commission released new hospital standards emphasizing the need for health care providers to address the unique concerns of patients who face "communication barriers" including speech, language and hearing disorders, as well as patients who do not speak English as a first language (Joint Commission, 2010), (<http://www.patientprovidercommunication.org>). These standards provide a renewed impetus and opportunity for physicians (and other health care providers) to learn how to meet the needs of patients with communication disorders during medical interactions.

Triadic Communication during Medical Interactions

Most training and research surrounding patient-provider communication during medical interactions is dyadic in nature, exploring interactions between patients and physicians (Cahill & Papageorgiou, 2007; Cordella, 2011). However, caregivers often accompany patients to their medical interactions, creating more of a triadic communication situation (Cordella, 2011; Karnieli-Miller, Werner, Neufeld-Kroszynski, & Eidelman, 2012; Laidsaar-Powell et al., 2013; Sakai & Carpenter, 2011). Caregivers are typically comprised of family, friends, neighbors or others who care for those who are elderly, disabled, or experience chronic or terminal illnesses (Levine, 2004).

Research regarding triadic communication during medical interactions is limited, historically focusing on pediatric or geriatric patient populations where patients are often unable to participate in shared-decision making and need someone to speak for them (Cahill & Papageorgiou, 2007). Additionally, while research in effective patient-provider communication during medical interactions acknowledges the emergence and importance of triadic medical interactions (Tsai, 2007), physicians are rarely provided training in how to effectively include caregivers in medical interactions. In fact, several research studies have called for an emphasis on communication skills training in this area (Karnieli-Miller et al., 2012; Law et al., 2005; Levine, 2004; Ziviani et al., 2004).

Dynamics of triadic communication. The conversational dynamics during triadic communication have been theorized to differ from those of dyadic communication (Tates & Meeuwesen, 2001). Simmel (1950) posited that the addition of a third person into a dyadic conversation can affect the structure and function of the interaction that occurs. For example,

when three people are involved in a conversation, there is less opportunity for each person to be heard than if the conversation were dyadic. Simmel also theorized that the third person in a communication triad plays one of three potential roles, all of which relate to their perception of their identity within the triad and the amount of power they wield in the interaction. The third person may serve to mediate between the other two people, to exploit one or both of them, or to become antagonistic to one or both of them (Adams & Gardiner, 2005). In this way, the third member of a triad (e.g. the caregiver) can influence the dynamics of the conversation by either enabling or disabling communication between the first two people (e.g. the patient and physician) (Sakai & Carpenter, 2011).

Caregivers in medical interactions. The importance of caregivers being present during medical interactions has been recognized in research on improving patient outcomes in health care (Cordella, 2011). Caregivers routinely accompany patients with communication disorders to their medical appointments with physicians. Typically comprised of the patients' close family members, including spouses, partners, or adult children, these caregivers often attempt to facilitate communication with physicians and assist patients with making important medical decisions.

Caregivers can have significant effects on communication during medical interactions. They can either help facilitate communication between patients and physicians, or interfere with this process (Karnieli-Miller et al., 2012; Laidsaar-Powell et al., 2013; Sakai & Carpenter, 2011). Caregivers can advocate for patients, help interpret the patients' perspectives for physicians, and help patients implement treatment recommendations. They sometimes even speak for patients when they are unable to speak for themselves. However, while caregivers of patients with communication disorders are often related to the patients and know them well, they may not

reliably communicate the patients' perspectives to physicians or other health care providers (Doyle et al., 2013). Additionally, caregivers' perceptions may not always accurately reflect patients' views and health care decisions, and they may have their own agenda for obtaining the health care services they think patients need which may not reflect the patients' actual needs or perspectives.

Research suggests that the roles caregivers play during triadic medical interactions are also not well defined (Adams & Gardiner, 2005; Cordella, 2011). While the roles of patients and physicians have recently been shifting under a model of patient-centered care to provide the patient with more autonomy and opportunity for shared-decision making, caregivers' roles have become somewhat blurry and often walk the line between overlapping with those of health care providers and patients alike. For example, as part of a series of research studies by Helmsley et al (2008a-c) patients with cerebral palsy, their caregivers, and hospital staff were asked to describe the roles caregivers play in triadic medical interactions during hospitalization. While all three stakeholders agreed that caregivers are responsible for advocating for patients, providing medical knowledge about patients, and "bridging the communication gap" between patients and health care providers, caregivers further defined their role as both protecting the patient from unskilled or untrained providers as well as providing direct care. Hospital staff, however, did not believe it was the caregivers' role to provide direct care to patients during hospitalization, and that caregivers often had trouble 'letting go' of providing this care when staff were available and trained to do so.

In a more recent study, Karnielle-Miller and colleagues (2012) examined triadic communication during a series of initial memory clinic visits involving patients newly diagnosed with Alzheimer's disease, companions (caregivers) that accompanied them to their visits, and

physicians. Researchers analyzed twenty-five real time observations of medical interactions as well as semi-structured interviews conducted with all participants. Results suggested that although sometimes helpful, the companions' presence often complicated the process of communication during medical interactions, and companions were often confused as to what their role in the interaction should be. In addition, although physicians controlled the flow of communication, they often struggled to effectively integrate the companions into these interactions.

The presence of family caregivers regularly creates triadic medical interactions for patients with communication disorders. However, limited research currently exists focused on exploring the experiences and perspectives of caregivers during these interactions, as well as the roles each of the stakeholders play. Having a better understanding of the roles caregivers play during triadic medical interactions can help to provide improved training to physicians on how to integrate caregivers into these interactions more effectively.

Models of Communication in Medical Interactions

Having a theoretical model that explains and predicts communication during triadic medical interactions can serve as a basis for conducting research or designing interventions to improve communication during these interactions. However, relevant models that can adequately represent triadic communication during medical interactions seem to be lacking in research and practice (Laidsaar-Powell et al., 2013). The following represents a brief historical perspective on the development of selected models of communication and their limitations in helping to explain medical interactions. Communication Accommodation Theory (CAT) is then described and discussed in terms of its potential feasibility in serving as a framework from which to develop a

model of triadic communication during medical interactions involving patients with communication disorders.

History of Models of Communication

Various theoretical frameworks have been offered to explain the process of communication. However, most fall short of adequately representing typical communication interactions between individuals, including those between patients and physicians. Some models are too simplistic, proposing either unilateral communication of a message between a speaker and a listener (Shannon, 1948), or bidirectional communication only to the extent that the listener provides feedback to the speaker regarding his or her message (Weiner, 1986). These models do not represent typical communication interactions between individuals in which bidirectional communication regularly occurs, often with communication partners alternating between the roles of speaker and listener. These models also fail to consider the context in which communication takes place, which can often affect the transmission of the message. For example, a casual conversation between two friends that run into each other at the grocery store may look very different than a conversation between a police officer and an individual that has been pulled over for speeding. Both conversations will likely involve each individual alternating between the roles of speaker and listener, but the tone and length of each conversation as well as the physical environment in which they occur may be different. Additionally, the roles of each individual and the relative power associated with each of those roles are different, which can affect the interaction. Similarly, it is important to consider the context in which medical interactions occur. For example, time constraints may cause a physician's communication with a patient to be abbreviated and focused more on gathering specific medical information than establishing rapport or figuring out how these issues are affecting the patient's daily life.

In 2004, Foulger proposed an Ecological Model of Communication which seems to better represent typical communication interactions, including medical interactions between patients and physicians. In Foulger's model, communication partners alternate roles between sender and receiver of messages that are affected by the context in which they are sent. This context can be both external to the partners (i.e. the physical environment) and internal (i.e. each individual's feelings, attitudes, or beliefs). In other words, the context becomes the filter through which the message is sent (Foulger, 2004). Unfortunately, this model seems to fall short of representing interactions involving individuals with communication disorders. In this model, the communication skills and abilities of each conversation partner are assumed to be adequate and equal. This model does not account for one of the partners having communication difficulties, whether those difficulties stems from lack of knowledge and experience communicating within a certain context (i.e. non-native speakers of a language communicating with limited vocabulary to native speakers of that language) or from a communication disorder (i.e. aphasia). This model also fails to account for communication breakdowns that may occur.

Communication Accommodation Theory

Communication Accommodation Theory (CAT) has been offered as a potential explanation for the process behind interactions between communication partners whose communication skills and abilities are not equal. Originally developed by Giles in 1971, this interaction-centered theory posits that individuals often adjust how they communicate based on with whom they are speaking and the context in which communication takes place (Giles & Ogay, 2007; Williams, 1999). It provides a framework to explain and predict why and how individuals adjust their communication behaviors during conversations (Bylund, Peterson, & Cameron, 2012; D'Agostino & Bylund, 2011). In other words, CAT offers an explanation as to

why the same individual may use different vocabulary, intonation, gestures, and other verbal and nonverbal *accommodations* among various listeners based on characteristics such as age, gender, ethnicity and culture (Baxter & Braithwaite, 2008; Giles & Ogay, 2007). These adjustments occur either to more closely approximate a listener's communication style or to meet his or her needs to improve the effectiveness of communication (Gallois, Ogay, & Giles, 2005; Giles & Ogay, 2007; Ylanne, 2008).

The process of communication accommodation. Central to CAT is the concept of convergence. Convergence includes the steps involved in accommodating one's communication behaviors to those of another communication partner (Baxter & Braithwaite, 2008). Convergence can involve switching to another communication partner's language or dialect. It can also encompass using different vocabulary, intonation, or nonverbal gestures one may not otherwise employ. Two types of convergence are included as part of CAT: upward and downward. Upward convergence involves adopting a more advanced speech pattern, vocabulary, or accent to gain social acceptance or improve comprehension. Downward convergence involves using a more basic or elementary dialect, speech pattern, or vocabulary for the same reason (Baxter & Braithwaite, 2008; Giles & Powesland, 1975). For example, a college graduate student may use advanced vocabulary to employ upward convergence when engaging in a conversation with her professor in order for the professor to look favorably on her. The same student may use more colloquial vocabulary to use downward convergence while teaching a course to undergraduates in order to improve their comprehension of concepts taught in the course.

According to CAT, communication partners affect one another simultaneously within the same interaction, causing them to frequently alternate between the roles of speaker and listener (D'Agostino & Bylund, 2011). When one assumes the role of speaker during a communication

“transaction” (i.e. when a message is sent to a communication partner), he or she is responsible for determining whether accommodations are needed for a given listener, deciding which accommodations should be used, implementing these accommodations, and monitoring whether or not they are successful in improving communication. Conversely, when one adopts the role of listener during a transaction, he or she is responsible for initially providing cues (verbal or non-verbal) to the speaker regarding whether or not accommodations are needed, as well as whether the accommodations speakers use are successful in improving communication (and need to be maintained) or unsuccessful (and need to be modified or amplified).

Individuals typically make accommodations based on stereotypes about their communication partners (Baxter & Braithwaite, 2008). Stereotypes are often used to develop perceptions and assumptions regarding a partner’s communication abilities, and to determine which accommodations should be used with that communication partner for improved comprehension. For example, people often assume that individuals with foreign accents who learned to speak English as a second language require the use of more simplified vocabulary and sentence structure in order to participate in a conversation in English.

Unfortunately, basing communication accommodations on stereotypes can lead to faulty perceptions or expectations about the communication skills of others. Speakers are not always correct in the assumptions they make about listeners and vice versa (Baxter & Braithwaite, 2008). People with foreign accents may have a superior grasp on the English language. Individuals who are hard-of-hearing may have just been fitted with hearing aids that enable them to hear speakers without difficulty during conversation. In this way, some accommodations individuals make can “miss the mark.” Over-accommodation can occur, in which speakers make changes to their communication behaviors when none are needed. Conversely, speakers can also

fail to make changes to communication behaviors when changes are necessary, resulting in under-accommodation (Worrall & Hickson, 2003; Ylanne, 2008).

Over-accommodation and under-accommodation. During communication interactions, over- or under-accommodation can occur for a variety of reasons (Williams, 1999). First, speakers may be unaware of specific cultural norms of listeners. Lack of awareness regarding these norms can lead speakers to adjust their communication style in a potentially inappropriate and even offensive way. Additionally, speakers may lack the knowledge or skills to successfully make accommodations based on the listener's needs. Speakers may recognize based on listeners' verbal or nonverbal cues that communication may not be progressing successfully, but are unaware of how to make the necessary adjustments to improve communication. For example, an English-speaking physician providing information to a patient who speaks a different language may be aware the patient is not understanding, but may raise the volume of his or her voice in an attempt to help the patient understand, thus providing over-accommodation. Lack of proper accommodation may also be due to speakers purposefully trying to miscommunicate. If speakers are uninterested in making successful accommodations to meet the needs of listeners or are trying to emphasize social or cultural differences between them and their listeners, they may choose to purposefully not make accommodations or make inappropriate accommodations. For example, a physician may choose to use complex medical jargon when speaking to a patient instead of using lay language during a medical interaction to emphasize the physician's authoritative role over the patient. Finally, listeners may be responsible for poor accommodation. The verbal or nonverbal cues listeners give to speakers regarding the effectiveness of communication may be unsuccessful or insufficient for speakers to appropriately calibrate the accommodations they make.

Thus, CAT makes certain assumptions about speakers and listeners in order for successful accommodation to occur during communication interactions. First, the individual adopting the role of the speaker is assumed to have judged the level of accommodation needed to successfully communicate with the listener before beginning the conversation (whether or not these judgments are accurate). Second, the speaker is assumed to have a conscious awareness of the communicative context in which the conversation takes place in order to select appropriate accommodations (Ylanne, 2008). This can include the physical, sociohistorical, and temporal context, as well as the communication history of both partners. Third, CAT assumes the listener is capable of providing the speaker with sufficient and appropriate cues to indicate whether or not communication is successful, and that the speaker is able to recognize the meaning behind these listener cues. Finally, the speaker is assumed to have the knowledge and skills to be able to make the necessary accommodations to initiate and maintain a successful interaction with a listener (Ylanne, 2008). Again, because communication partners often alternate between the roles of speaker and listener during interactions, it is assumed using CAT that each partner is able to execute both roles for accommodation to be effective.

Research has supported the use of CAT to explore medical interactions between patients and their physicians. CAT has additionally been used to explain communication interactions involving individuals with communication disorders. The following sections will discuss the application of CAT in medical interactions, including those involving patients with communication disorders. These sections will also discuss potential limitations to the application of CAT in these interactions, and propose a revised model of CAT to potentially address these limitations.

CAT and Medical Interactions

In 2012, Bylund and colleagues provided an overview and description of selected interpersonal communication theories and how they have been applied to health care communication research. The authors discussed CAT as an interaction-centered theory that focuses on the communication interactions between patients and physicians. The authors also commented that, to date, CAT has had limited application in health care communication research.

Since the 1990s, CAT has been used to explain and evaluate the process behind communication during medical interactions between patients and their physicians (D'Agostino & Bylund, 2011; Hewett, Watson, Gallois, Ward, & Leggett, 2009; Watson & Gallois, 1998; Wright et al., 2013). For example, in a 1998 study by Watson and Gallois, independent raters examined video recordings of actual medical interactions between patients and providers to identify the presence or absence of specific nurturing communication behaviors as part of an effort to operationalize the strategies and goals of CAT during these interactions. Results of this study suggested that providers used these nurturing communication behaviors more often when attempting to individualize patients' care (versus generalizing care based on patient groups), and that patients rated these behaviors favorably. In 2007, Hajek and colleagues explored the relationship between patients' perceptions of physicians' accommodations and their inclination to comply with physicians' recommendations. In this study, 112 participants completed a telephone survey in which they were asked to think about their most recent medical visit and to answer questions about their physician's communication skills during that visit, as well as the likelihood they would follow treatment recommendations that physician prescribed. Results of this study indicated that perceptions of the accommodations that physicians made to meet the

needs of the patients directly predicted patients' inclinations to follow treatment recommendations.

In a more recent study, Baker et al. (2011) conducted in-depth interviews with patients diagnosed with musculoskeletal disorders and their physicians to investigate how they communicated with one another during medical interactions. Results of this study suggested that the priorities doctors and patients had for managing musculoskeletal disorders often differed, and that they should focus on recognizing these differences and making communication accommodations accordingly for one another to potentially help improve the effectiveness of treatment.

Based on the results of these studies, CAT seems to serve as a useful theoretical framework for research exploring the process of communication that occurs between patients and physicians during medical interactions. This interaction-centered theory has been described as an 'insightful' and 'easily applied' framework for examining and predicting communication behaviors during medical interactions (Hehl & McDonald, 2012). Physicians often modify the way they communicate to improve both the relationship and rapport they have with their patients, as well as patients' comprehension of important medical information (Duggan, Bradshaw, Swergold, & Altman, 2011). CAT reflects the mutual construction of communication during these interactions (D'Agostino & Bylund, 2011). CAT also acknowledges the context in which communication takes place during medical interactions, including the roles that patients and physicians assume and relative power and authority associated with those roles.

However, research that has explored the application of CAT to medical interactions has some significant limitations. First, this research consistently assumes physicians to be in the role

of speaker, responsible for making accommodations to their communication to meet the needs of patients, who are assumed to consistently adopt the role of listener. This research assumes that physicians and patients do not alternate their roles as speakers and listeners during these interactions, and that patients are not also making accommodations, or changing how they communicate, to help improve communication with physicians. However, patients frequently take on the role of speaker when they are communicating with physicians during medical interactions, and they may need to make accommodations for communication to be effective with physicians. For example, patients often assume that physicians have a limited amount of time to spend with them during medical interactions. For this reason, they may make accommodations for physicians by being brief, or “getting to the point,” in discussing the reason for the medical visit or in describing their symptoms rather than offering an extended narrative explanation. Assuming physicians are consistently in the role of speaker during medical interactions also does not consider information sharing that occurs between patients and physicians. Specifically, this assumption does not address shared decision-making between patients and physicians that is advocated for in health care today (Makoul & Clayman, 2006).

In addition, research exploring the application of CAT to medical interactions also assumes that communication during these interactions is dyadic, solely between patients and their physicians. However, as previously discussed patients may have family members or caregivers with them who also participate in the medical interaction, creating a triadic medical interaction. Consequently, little research exists exploring the application of CAT to triadic medical interactions.

In medical education, physicians are taught to modify the way they communicate during medical interactions based on their patients’ needs and the context surrounding the interaction.

However, the dynamics of medical interactions involving patients with communication disorders may not be the same as those of patients without communication difficulties. Thus, it is important to examine the extent to which CAT has been used in regards to medical interactions involving this patient population.

CAT and Patients with Communication Disorders

CAT has recently been applied in research exploring how well physicians can make accommodations to their communication to meet the needs of patients with disabilities during medical interactions. Duggan et al. (2011) studied the process by which third and fourth year medical students attempted to establish rapport with standardized patients trained to exhibit physical disabilities. Results of this study suggested that these medical students had difficulty establishing rapport with patients exhibiting disabilities, often “crossing the boundaries” of effectively establishing rapport by using a variety of inappropriate, and often unnecessary, communication behaviors (p. 25). These behaviors included the use of baby talk, exhibiting a closed posture or awkward body language, use of inappropriate pitch and volume, assuming relationships between patients and caregivers who accompanied them, and responding positively to negative or neutral information from patients. Medical students’ overuse of inappropriate communication behaviors created an over-accommodation to the patients’ disabilities. However, none of the standardized patients in this study were trained to portray patients with communication disabilities, and these interactions were dyadic in nature as no “caregivers” were present during the study.

CAT has also been used to offer explanations for the process of communication during general interactions with individuals with communication disorders. Worrall and Hickson (2003)

applied CAT to explain interactions with older adults with communication disorders. Figure 1 depicts a model the authors use to apply CAT to an interaction involving an older adult with a hearing impairment, including how under- and over-accommodation can potentially occur during this communication interaction. According to this model, successful accommodation occurs when the listener (i.e. the individual with the hearing impairment) provides cues to the speaker indicating he or she did not hear what was communicated, the speaker makes appropriate accommodations to improve communication (i.e. increases his or her volume), the listener responds with cues indicating communication has improved, and the speaker maintains the accommodations that were made. This model depicts under-accommodation as the speaker not recognizing the initial cues provided by the listener and failing to accommodate his or her communication to meet the listener's needs. Over-accommodation is depicted as the speaker making accommodations based on stereotypes about the listener as an older individual (i.e. assuming that the individual has a cognitive loss instead of a hearing impairment) and making accommodations that are inappropriate for an individual with a hearing loss.

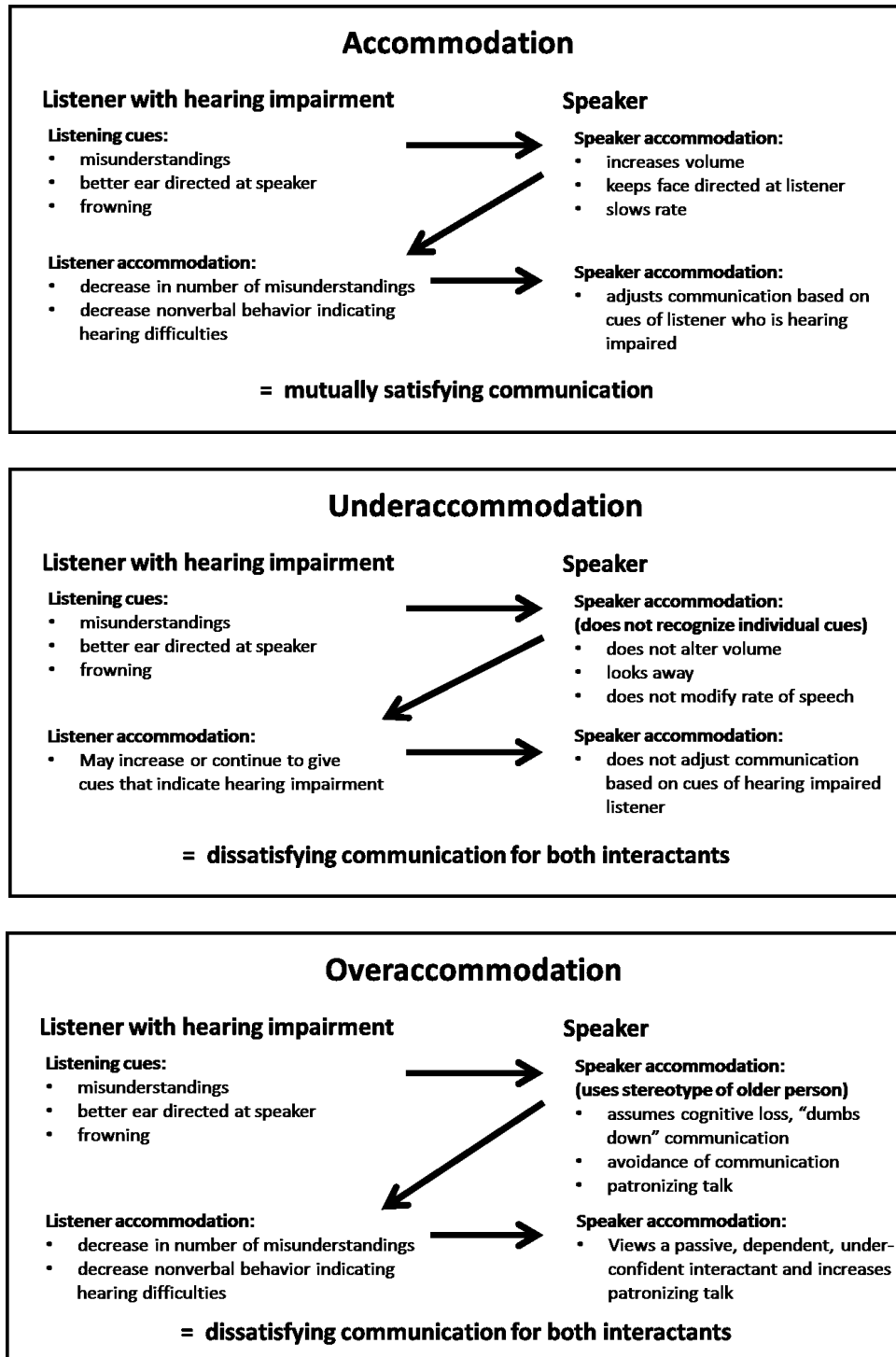


Figure 1. Communication Accommodation Theory applied to an older person with hearing impairment (reproduced from Worrall and Hickson, 2003).

Worrall and Hickson's illustration of CAT seems to adequately explain the process of accommodation for individuals with communication disorders during conversational interactions. However, there are significant limitations to this application of CAT. First, Worrall and Hickson's model assumes that individuals with communication disorders adopt the listener role during conversational interactions, responding passively to speakers only to provide cues regarding the effectiveness of their accommodations. Perhaps this is appropriate when the communication disorder is limited to a hearing impairment. However, it is possible that this model of CAT may need to be modified or expanded to include receptive and expressive communication when considering other communication disorders. For example, an individual with Parkinson's disease exhibiting decreased vocal loudness may need to make accommodations to help the listener understand him, such as increasing his vocal loudness and turning towards the listener so he or she is able to read the speaker's lips if necessary. The speaker is then also responsible for evaluating whether or not the listener heard him based on the cues that listener gives him about the message.

A second limitation to Worrall and Hickson's model is that it suggests that communication interactions begin with speakers making accommodations based on observed listener behaviors, such as body language, facial expressions, or intonation. What this model does not capture, however, is the initial message that a speaker sends to the listener to initiate the interaction, including potential accommodations the speaker makes before receiving any feedback from the listener. Speakers may implement accommodations based on preconceived stereotypes and assumptions that exist about individuals with communication disorders before the interaction even begins. Consequently, under- and over-accommodation can occur as the speaker is initiating the conversation; it is not necessarily limited to occurring as a response to

the listener's observed communication behaviors as this model suggests. This seems especially true during medical interactions, where physicians often have access to information about their patients with communication disorders from their medical chart. Having access to this information can lead to physicians forming assumptions about these patients and the potential accommodations that need to be made to meet their communication needs before the interactions even begin.

A final limitation of this model is the assumption that interactions with individuals with communication disorders are dyadic, consisting of only one other person. It cannot be assumed that these individuals engage only in dyadic interactions. Medical interactions, as previously discussed, are also not always dyadic in nature. Caregivers regularly attend medical appointments with individuals with communication disorders, potentially creating triadic medical interactions with physicians. The presence of a caregiver has the potential to change the dynamics of these medical interactions, creating uncertainty as to the adequacy of CAT in serving as a theoretical framework for explaining communication during these interactions.

Little research exists that uses CAT to directly explore the experiences of patients with communication disorders and their caregivers during triadic medical interactions with physicians. As a result, much remains unknown regarding communication during these interactions and whether or not this theoretical framework can be used to adequately represent this process. In order to evaluate whether CAT is a viable theory to explain communication during triadic medical interactions involving patients with communication disorders, the perspectives and experiences of these patients and their caregivers who have participated in these interactions need to be better understood. Learning more about their experiences and perspectives will help inform whether they perceive physicians to regularly make changes in

communication that result in over- or under-accommodation during these interactions. It may also provide some insight into whether they feel their physicians have been able to successfully adjust their communication to facilitate improved comprehension of information during these interactions, and which accommodations their physicians used. Finally, it can provide a better understanding of how patients with communication disorders adjust the way they communicate to make accommodations for physicians who struggle to understand them.

Despite the limitations of Worrall and Hickson's model and the lack of research applying CAT to triadic medical interactions involving patients with communication disorders, this theoretical framework shows potential for being useful in helping explain communication during these medical interactions. Figure 2 represents a proposed revision of the CAT model, hypothesizing how successful accommodation may occur during a triadic medical interaction involving a patient with severe dysarthria, his family caregiver, and his physician. This figure also represents how over- and under-accommodation may occur in this scenario.

In this proposed revision, the labels "speaker" and "listener" are not used. Instead, each member of the interaction is labeled as either *patient*, *caregiver*, or *physician*. In this CAT model, the solid arrow indicates a message sent between the physician and the patient during the interaction. The arrow is bidirectional to signal that the message can originate from either communicator. The bidirectional dotted arrow extending between the patient and physician represents feedback given to the message sender about the message. This feedback may be verbal or nonverbal, and may either be a response to the message (i.e. answering a question) or cues to indicate whether or not the message was understood (i.e. a confused look, or a head nod indicating comprehension). The bidirectional dotted lines extending from the caregiver to both other communicators indicates potential interactions the patient or physician may have with

caregiver during the time the message is sent and feedback is received. The circle encompassing all three communicators represents the context in which communication is occurring, which can potentially affect the transmission of the message.

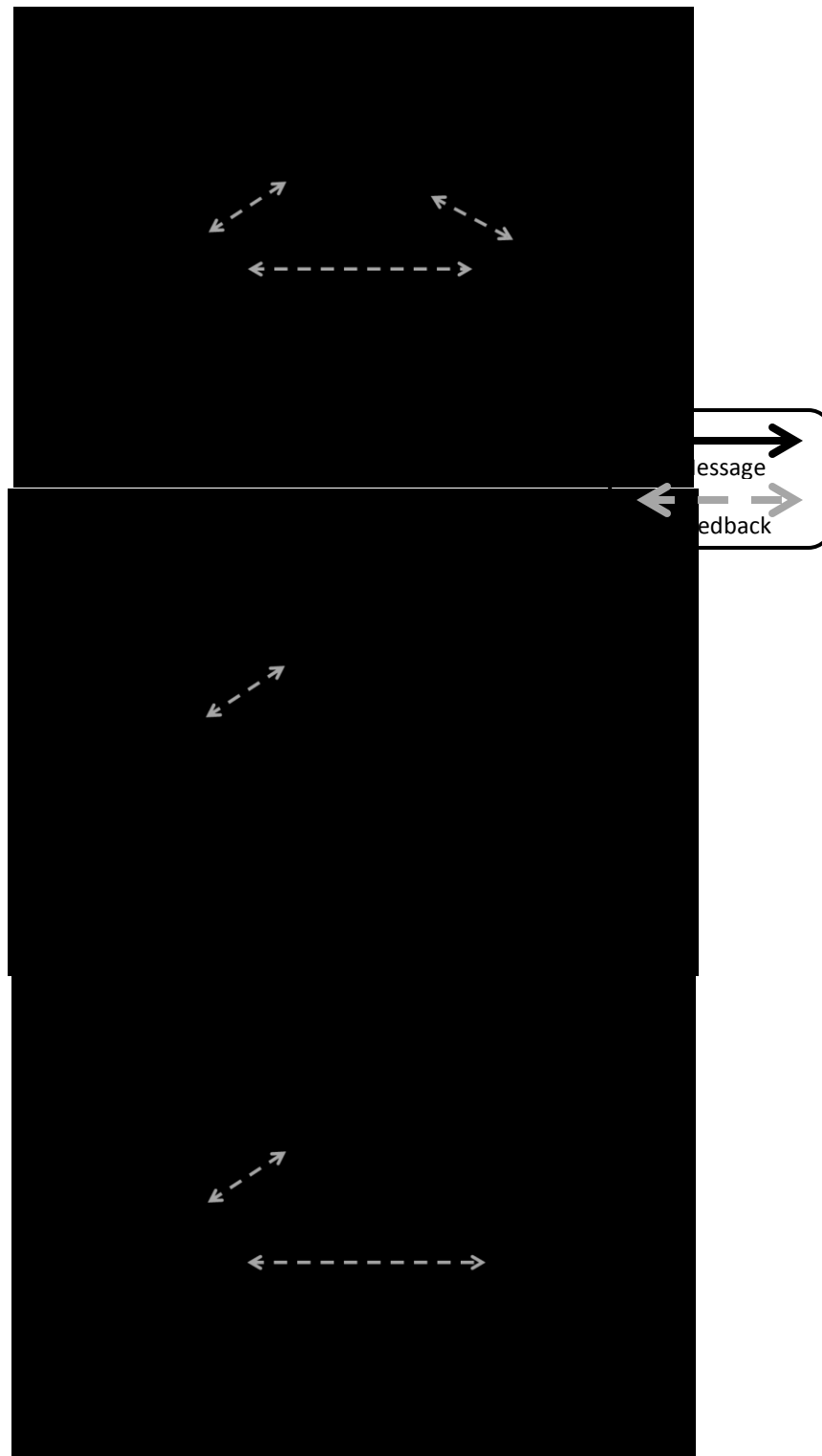


Figure 2. Proposed revision for a model of CAT representing triadic communication involving patients with communication disorders, caregivers, and physicians. Accommodation is depicted by the message (solid arrow) remaining between the patient and physician while feedback is used (dotted arrows) to influence changes in communication. Under-accommodation is depicted by the message remaining between the physician and patient while no feedback is being used by the physician (elimination of dotted arrows) to influence changes in communication. Over-accommodation is depicted by the message occurring between the physician and caregiver, bypassing the patient, despite feedback indicating the patient may be able to participate in the interaction.

As an example of how this revised model of accommodation might function, let us assume the physician asks the patient with dysarthria a question related to how he is feeling, indicated by the solid arrow between them. If the patient understands the question he may offer a response to the question directly to the physician, again indicated by the solid arrow between them. However, because the patient has dysarthria his response may not be understood by physician. In this case, the physician may send the patient a nonverbal cue (i.e. a confused look) to signal the response was not understood, indicated by the dotted arrow between them. In an effort to help the physician better understand his message, the patient may make accommodations to his speech by re-sending his message using a slowed rate of speech and over-exaggerated articulation. The physician may now understand the message, and may send the patient another signal (verbal or nonverbal) that the message was understood. If this repeated message was again not understood, the caregiver may enter the interaction to repair the communication breakdown by either ‘interpreting’ the message to the physician (if she understood it herself), or first clarifying the patient’s message and then translating it to the physician. Thus in a successful accommodation situation, the patient and physician are the primary communication partners with caregiver acting as a ‘interpreter’ when communication breakdowns occur and are not able to be resolved between these primary partners.

Figure 2 also depicts how under- and over-accommodation may occur using this revised model of CAT. Using the same scenario of the physician asking the patient a question related to how he is feeling, under-accommodation may occur if the physician does not make any accommodations for the patient while initially sending a message, as well as ignoring potential feedback from the patient (and possibly the caregiver) that the message was not understood, and continues to repeat the question or send future messages in the same way. In this case, under-

accommodation is represented by elimination of the dotted “feedback” arrows between the physician and the other communicators in the medical interaction. Over-accommodation may also occur during this interaction. An example of over-accommodation may involve the physician assuming that the patient will be unable to answer the question he is about to ask based on the patient’s diagnosis of dysarthria, and instead asks the question to the caregiver who is assumed to be able to answer the question because of her familiarity with the patient. In this scenario, the physician is choosing to make an accommodation to his communication by bypassing the patient altogether and using the ‘interpreter’ when the patient may be able to answer the question. Over-accommodation in this case is represented by the solid arrow between the physician and the caregiver.

It is important to note that the proposed application of CAT in Figure 2 represents a single communication “transaction,” consisting of a single message sent from one communicator to another, as well as the feedback that is given to the sender about that message. Once the sender receives this feedback, the next communication transaction begins which may look very different depending on whether or not the speaker chooses to make any (or different) accommodations based on this feedback. For example, the physician may initially adjust his communication too much (over-accommodation) at the start of a medical interaction by speaking with the caregiver instead of the patient if he feels the patient is unable to respond to the question. However, if the feedback the physician receives from this over-accommodation indicates that the patient is capable of answering his question (i.e. the caregiver redirects the physician to ask the patient the question), the physician may then turn to the patient and re-ask the question. Thus, each successive communication ‘transaction’ during the medical interaction

may shift between under-accommodation, over-accommodation, or accommodation depending on the ‘success’ of that interaction, ideally moving towards achieving effective accommodation.

In summarizing this introduction, research suggests that patients with communication disorders experience diminished access to quality health care services and decreased overall health outcomes compared with the average patient population. Available research suggests that poor communication between these patients and their physicians may be responsible for these negative outcomes. However, exploring the perspectives and experiences of the stakeholders involved in triadic communication during these medical interactions can provide additional insight into how communication works (or breaks down) during medical interactions, how potential breakdowns can be avoided or repaired, and the specific roles that stakeholders play. In addition, it is currently unclear whether a theoretical framework adequately representing triadic communication during these medical interactions currently exists. The proposed revision to the CAT model represented in Figure 2 has not yet been evaluated using the communication experiences of these patients and their caregivers. Learning more about how patients with communication disorders and their caregivers experience medical interactions with physicians can help inform an appropriate working model of CAT, as well as communication skills training programs based on this model, which focuses on helping physicians improve interactions with this patient population. Improved communication during these medical interactions may in turn help patients with communication disorders increase their access to quality health care services, and improve their overall health outcomes.

Statement of the Problem

Patients with communication disorders are currently considered a vulnerable population in health care. They are often susceptible to increased medical errors and complications compared with patients without communication disorders. These problems typically stem from the lack of effective communication that often occurs between these patients and their physicians during medical interactions. As a result of ineffective patient-provider communication, patients with communication disorders often experience diminished access to quality care and decreased autonomy related making health-related decisions.

While the importance of improved communication between patients with communication disorders and their physicians has recently begun to be recognized in health care, physicians typically receive no instruction or training in facilitating communication with this patient population. Some research and training programs have emerged in an attempt to help fill these gaps in physicians' knowledge and clinical skill. However, much remains unclear about how triadic communication works during medical interactions involving patients with communication disorders, and a theoretical framework is lacking that adequately represents these interactions. Having a model of communication based on a theoretical framework, such as CAT, that can effectively explain and predict communication behaviors during these medical interactions can serve to inform the content of these training programs and future research in this area.

Providing a model-driven communication-skills training program to physicians focused on helping them facilitate improved communication with patients with communication disorders during triadic medical interactions can potentially improve this patient population's access to

quality health care services. Providing this training to physicians can also in turn create opportunities for these patients to participate in shared decision-making related to their care.

The purpose of this study is twofold: 1) to explore the perspectives of patients with communication disorders, their family caregivers, and physicians related to communication during medical interactions, and 2), to examine the relevance and appropriateness of CAT in explaining the process of communication during triadic medical interactions with this patient population.

Research Questions

1. What are the perspectives of individuals with communication disorders, their family caregivers, and physicians related to communication during medical interactions?
2. Does Communication Accommodation Theory (CAT) adequately represent triadic communication involving individuals with communication disorders, their family caregivers, and physicians during medical interactions? Specifically, which components of the CAT model are emphasized from the perspectives of these individuals, and which are not?

CHAPTER TWO: METHODS

The following section describes the methods used in conducting this qualitative research study. Included in this section are a summary of the procedures used for recruiting and providing consent for participants, data collection, data analysis, and ensuring data authenticity. For a list of study procedures, see Appendix A. Study methods were conducted with ethics approval from the Institutional Review Board at the University of Washington (application number 43078).

Design

As the research questions for this study focused on exploring the perspectives and lived experiences of participants, qualitative research methods based on grounded theory were used to collect and analyze data. Investigators utilized semi-structured interviews to gather narrative data from individuals with communication disorders, their family caregivers, and physicians related to their experiences communicating during triadic medical interactions. Data were analyzed to develop themes surrounding communication during these medical interactions based on participants' experiences and perspectives, as well as to investigate whether CAT seems to represent the process of communication during these medical interactions.

Grounded theory is among the most popular and influential types of qualitative research used when developing or testing a theory (Strauss & Corbin, 1997). This research perspective involves using participant data as the basis of either developing a new theory or analyzing an existing theory to better understand a social phenomenon (Glaser & Strauss, 1967). In this way, the theory is "grounded" in the experiences and perspectives of the participants. Traditionally in grounded theory, collected data are coded and analyzed to develop concepts and themes from which a theory is developed or tested. However, because CAT already exists, the purpose of this

study was not to develop this theory solely from the collected data. Instead, this study used the collected data to investigate whether this existing theory could also be applied to represent triadic communication during medical interactions involving patients with communication disorders.

Participants

Individuals with communication disorders, their family caregivers, and physicians were recruited to participate in this study. The author of this dissertation (referred to in this document as the lead researcher) recruited all participants, determined their eligibility, and provided informed consent. The following section describes the procedures the lead researcher used for recruiting participants, determining eligibility, and providing consent for this study.

Recruitment

Participants represented a convenience sample of patients, their family caregivers, and physicians from the Pacific Northwest area. Patients and their family caregivers were recruited as pairs from the University of Washington Speech and Hearing Clinic (UWSHC) and the UW Aphasia Registry and Repository. Advertisements were posted in the reception area of the UWSHC (see Appendix B), and the lead researcher made several presentations to various client groups attending the clinic regarding the purpose and procedures of the study. Clients' questions were answered and they were provided with the lead researcher's contact information in case they had additional questions or were interested in participating in the study. Recruitment emails (see Appendix C) were also sent via the UW Aphasia Registry listserv. Physicians were either nominated by patient and caregiver participant pairs, or recruited through hospitals within UW Medicine (Affiliated Medical Centers within the University of Washington School of Medicine) through distribution of recruitment flyers (see Appendix D) and word of mouth about the study.

Interested physicians were given the lead researcher's contact information in case they had questions about the study or were interested in participating.

Eligibility

Potential participants contacted the lead researcher, who then screened them for eligibility. To be eligible, potential participants were required to meet specific eligibility criteria. Once deemed eligible, participants were enrolled in the study, and initial interviews were scheduled.

Inclusion criteria for participants with communication disorders (referred to in this document as "patients") were (1) a diagnosed acquired neurological communication disorder severe enough to interfere with daily communication (determined by the lead investigator during each patient's initial screening), including one or more of the following: expressive and/or receptive aphasia, apraxia of speech, or dysarthria, (2) the capability of answering interview questions with or without assistance from a licensed SLP conducting the interviews, and without assistance from their caregiver (in order to be interviewed individually during the study), and (3) at least 18 years of age. Patients utilizing augmentative and alternative communication (AAC) devices were considered as participants for this study provided they were capable of answering interview questions without assistance from their caregivers. Patients were excluded from the study if they attended medical visits without a caregiver or if they were unable to answer interview questions despite assistance from their caregiver or a licensed SLP.

Inclusion criteria for caregivers were (1) an immediate family member nominated by a patient (i.e. spouse, partner, adult child), (2) at least 18 years of age, and (3) had attended at least one medical appointment with the nominating patient that involved a physician in the six months

prior to participating in the study. This requirement allowed caregivers to comment on communication interactions between patients and their physician(s). Caregivers were excluded if they were not immediate family or had not attended a medical appointment with the nominating patient involving a physician in the previous six months.

Inclusion criterion for physicians was recent clinical experience involving patients with communication disorders. Specifically, they needed to have had face-to-face contact with either the nominating patient or at least 2-3 other patients diagnosed with communication disorders within six months prior to participating in the study. Physicians were not required to practice in any particular area of medical specialty to be eligible for this study. Physicians were excluded if they had not had face-to-face contact with a patient who had a communication disorder in the previous six months.

Consent

Prior to the start of their first interview, participants were asked to sign copies of an informed consent form after it had been explained to them by the lead researcher. When explaining the consent form to patients, the lead researcher used communication strategies as appropriate to improve the patients' comprehension of the information including: simplifying the language used in presenting the information, speaking slowly, using gestures and keyword writing, and checking periodically for the patient's understanding of the information. The lead researcher also answered any questions participants had about the consent form or the study itself. While the entire consent form was explained to patient and caregiver participants before the initial interview began, the last section of the consent form regarding the use of audio and video recordings was not discussed and signed until the follow-up individual interviews were completed. This allowed patients and caregivers the opportunity to decide whether to allow the

recordings to be used for purposes other than solely for data analysis after they had completed their interviews and knew the content of their responses. See Appendices E-G for a copy of the consent form for each participant group.

Data Collection

Interviews

Data were collected in face-to-face semi-structured qualitative interviews. All interviews were conducted by either one or two licensed speech-language pathologists with experience in qualitative interviewing methods. Patients and caregivers took part in two interviews; an initial joint interview, and a second follow-up individual interview. During the first interview, the patient/caregiver pair was interviewed jointly by the lead researcher and one of two secondary members of the research team. Secondary researchers were members of the lead researcher's dissertation committee, who consulted on and assisted with conducting participant interviews. Initial interviews allowed patients and caregivers the opportunity to provide their joint perspectives on communication during medical interactions with physicians. The second interview was scheduled 1-2 weeks after the first so that the first interview could be transcribed and discussed by the research team. During the second interview, patients were interviewed by the lead researcher and their caregivers were interviewed separately by one of the secondary researchers. As part of the second interview, impressions from the initial interview were shared with participants for confirmation of content, and to allow participants to expand on what they had previously said. In addition, second interviews allowed patients and caregivers to share their individual perspectives in their own words. Each interview lasted between 30-75 minutes with

breaks as needed. Physicians took part in a single individual interview conducted by the lead researcher. Each physician interview lasted approximately 20-30 minutes with breaks as needed.

All interviews were scheduled on a day and time that was convenient for participants. Patients and caregivers were given the option of being interviewed at the University of Washington Speech and Hearing Clinic (UWSHC), in their homes, or in a separate location of their choosing. All patients and caregivers chose to be interviewed either at UWSHC or at their homes. Physicians were also given the option to be interviewed at the clinic, at the medical facility where they work, or in a separate location of their choosing. All physicians chose to be interviewed at the medical facility in which they worked.

Data for this study included audio or video recordings of the interviews and written field notes taken by the researchers(s) during the interviews. All interviews involving patients were video recorded to capture both verbal and nonverbal communication that occurred. All other interviews were audio recorded. While both the lead and secondary researchers took field notes during each joint interview involving patients and caregivers, it was the secondary researcher's primary responsibility to do so while the lead researcher facilitated the interview. Field notes were intended to capture information deemed to be interesting, salient, or unique and were summarized by the researchers after the interview.

Interviews were conducted using a semi-structured style. Participants were asked open-ended questions as appropriate to elicit narrative responses, with researchers asking additional follow-up questions for elaboration or clarification. Researchers utilized interview guides for all participants during the first and second interviews. Separate interview guides were created for patients and caregivers during their joint and individual interviews, as well as for physician

interviews. A copy of these interview guides can be found in Appendices H-K. All interview guides provided researchers with a verbal script of instructions for participants, as well as a general list of open-ended interview questions related to their perspectives regarding communicating during medical interactions. Examples of interview questions for patients and caregivers were, “What is it like talking with your doctor(s)?” and “If you have trouble communicating with doctors, what do you do (if anything)?” Examples of interview questions for physicians were, “Tell me about your experiences communicating with patients with communication difficulties.” and “Are there any changes in your clinical practice that would help you talk with patients with communication difficulties?” At the beginning of their follow-up individual interviews, researchers asked patients and caregivers if there were specific topics or information brought up in their initial joint interview that they preferred not to discuss during the second interview. None of the participants chose to exclude any topics or information during their follow-up interviews.

For patient participants, the lead researcher established a reliable and consistent method of communication prior to asking questions from the interview guides. As with other participants, patients were initially asked open-ended interview questions from an interview guide in an effort to elicit a narrative response. If the patient was unable to answer an open-ended question during the interview, the researcher attempted to modify the question or the patient’s method of response so that he or she was able to reliably provide an answer while attempting to maintain the focus and intent of the original question. Common researcher modifications included slowing down the speed with which the question was asked, simplifying the language of the question (i.e. decreasing the number of words in the question), writing key words from either the question or the patient’s response for the patient to refer to as needed, repeating or

rephrasing the patient's answer to verify it was the answer he or she meant to say, and use of drawing and gestures to clarify information.

After each interview, researchers debriefed with one another, discussing what they felt was important from the interview as well as and how this information should be interpreted. They also compared their written notes, which allowed for continuity and coherence of information from the interviews.

Demographic Information

At the end of participants' final interviews, they were asked to provide demographic information. This information provided a more complete description of study participants. See Appendices L-N for a copy of the Demographic Information Form used to collect data from each participant group.

Demographic information collected from patients included their age, sex, medical diagnosis associated with their communication disorder (i.e. stroke), communication disorder diagnosis, and time since onset of their communication disorder. Patients were given the option of either completing Demographic Information Form themselves, or having the lead researcher help them complete the form. The lead researcher used various communication strategies as needed to help improve the patient's comprehension of information being obtained. Caregivers were also encouraged to help patients provide this information as needed. Demographic information collected from caregivers included their age, sex, relationship to the patients, how often they provide routine care (i.e. daily, weekly) for the patients, and how often they accompany the patients to medical visits with physicians. Demographic information collected from physicians included their sex, number of years they have been practicing, their medical

specialty area, the average number of patients with communication disorders they interact with on a weekly basis, and the level of training they have received in patient-provider communication with this patient population.

Interview Transcription

Written transcripts were created verbatim from audio and video recordings, including both verbal and non-speech communication. Patients' verbal expression during interviews was typically characterized by incomplete utterances, revisions, sound and word substitutions and non-word vocalizations. However, patients often supplemented their verbal communication with non-speech behaviors to express themselves, such as sound vocalizations, facial expressions, gestures, writing, or drawing. Video recordings of patient interviews helped the lead researcher better understand the patients' intended communication attempts by being able to watch them speaking, and allowed the patients' non-speech communication to be included in the transcription. Patients' speech was initially transcribed as much as possible and then was supplemented by descriptions of any non-speech communication behaviors that they also used to express themselves. Non-speech communication behaviors were represented in written transcripts using parentheses.

Field notes were used to supplement these transcripts to make them as complete and representative of the participants' responses as possible. The lead researcher transcribed joint and individual interviews involving patients and caregivers, and two undergraduate volunteers were recruited to each transcribe three of the physician interviews. To ensure reliability in the undergraduate volunteers' transcription of recordings, the lead researcher reviewed approximately 30% of their transcripts and compared them with the recordings to check for accuracy and consistency of transcription. When discrepancies were found, the lead researcher

and the transcriber reviewed the transcripts and audio recordings to resolve them. Discrepancies initially occurred multiple times (approximately 8-10 per transcript), consisting mostly of incorrectly transcribed words. Fewer discrepancies were found (approximately 1-2 per transcript) as the transcription process progressed. In addition, the volunteers were instructed to review approximately 10% of the transcripts the other volunteer had completed to improve the consistency of their transcriptions with one another.

Data Analysis

Coding Transcripts

Written transcripts were uploaded into Dedoose™ qualitative and mixed methods software to be coded and analyzed. Researchers assigned labels, or codes, to important segments of the written transcripts. This process of ‘coding’ these segments facilitated their sorting and organization based on their content, allowing themes to then be identified. Once the first two interviews had been transcribed and uploaded, the lead researcher and the two secondary researchers selected a transcript to read through separately and develop a list of initial codes based on concrete ideas or topics participants from that interview had discussed. Both the written transcript and the audio files were available to members of the research team as they reviewed the interview for coding. Codes were not created prior to reading through transcripts, but were instead developed and assigned as topics and concepts emerged through the participants’ words. For example, when discussing the role of the patient during a medical interaction, one of the caregivers (C5) stated, “The patient should also be an advocate so they have this information available for the doctor.” The code “patient” and the subcode “role” were applied to this statement. Similarly, when discussing the challenges of interacting with patients with

communication disorders, one physician (D2) stated, “It’s always a challenge, and I think the first challenge is simply the time required.” This statement was coded with “communication” and “barriers.” These same researchers then met to discuss their individual lists of codes to combine them into a single working list from which to code the remaining transcripts.

The lead researcher then selected and individually coded two additional transcripts in Dedoose using this updated list of codes. The same secondary researchers reviewed 10% of these coded transcripts, making notations (memos) in Dedoose as necessary. The researchers then met to discuss the coded transcripts to examine the appropriateness and level of reliability in the lead researcher’s coding, as well as whether the list of codes continued to represent the data. Disagreements in coding were few and they were discussed and resolved among the researchers, and the list of codes was modified accordingly. After disagreements were resolved, the lead researcher then proceeded to code the remaining participant interviews. The list of codes was modified several times throughout this process. Based on this list, the lead researcher developed a code book, which included the name and a short definition of each code. Once the researchers had reviewed this code book and agreed on the names and definitions of each code, this information was entered into Dedoose to be used for coding subsequent interviews. This code book was used to code transcripts across all participants. See Appendix O for a copy of this code book.

Developing Themes

Once the transcripts were coded, the lead researcher began a thematic analysis of the coded data. First, the data were sorted by each individual code, and the lead researcher summarized the content under each code across participants. These coded summaries provided the basis for developing initial themes to represent the experiences and perspectives of the

participants. The lead researcher met periodically with the same secondary researchers to discuss the themes and subthemes that were emerging from the data. During these discussions, modifications to themes and subthemes occurred, and any disagreements about themes and subthemes were discussed and resolved among the researchers. For example, coded data from all three types of participants were initially analyzed together. However, based on researcher discussions during the thematic analysis, the perspectives of patients and caregivers seemed to be distinct from those of physicians. For this reason, it was decided to analyze data from patients and caregivers separately from data collected from physicians. The lead researcher then finalized the themes and subthemes that seemed to best represent the coded data.

Ensuring Data Authenticity

Reliability

Before researchers can determine the authenticity of the data they have collected, they need to ensure the reliability of their data. Reliability is the extent to which collected data represents participants' responses to interview questions. During the data collection phase of this study, participant interviews were audio or video recorded and researchers took field notes. Comparisons among researchers' field notes were made after each interview and these notes were compared with verbatim transcripts of that interview to provide a method of checking to ensure the raw data collected represented what participants discussed. In addition, patients and caregivers were interviewed twice during the study. This gave the researchers an opportunity to compare data from the same participants to determine the consistency of information between interviews.

Credibility

In qualitative research, researchers are charged with the task of ensuring that data collected from participants is recorded and interpreted to authentically reflect their experiences and perspectives, as well as the perspectives of researchers who are interpreting this data. Two ways credibility can be established in qualitative research is through triangulation of data and member-checking. These methods were used in this study in an effort to provide a check and balance system both for the collection of data and interpretation.

Triangulation of data involves collecting and comparing data from multiple sources to minimize researcher biases. Multiple participant groups were recruited for this study. Patients, caregivers, and physicians represented different perspectives regarding communication during medical interactions. These differing perspectives contributed to a more comprehensive understanding of the topic. In addition, multiple researchers were involved in the collection and analysis of data during this study. This provided the opportunity for iterative comparisons of data among researchers during data analysis, leading to the development of codes and themes. It also helped to minimize any researcher bias, and helped to ensure that participants' perspectives were being accurately represented.

Member-checking also occurred in this study during the interview process and data analysis. During participant interviews, the researcher conducting the interview routinely restated or summarized information to participants to determine the accuracy of their field notes and their understanding of the participants' responses to questions. Providing patients and caregivers with a summary of their responses from the initial interview during their second interview also gave researchers some indication of whether these participants still felt what they had said during their initial interview continued to represent their perspectives. In addition, after completing an initial

thematic analysis from coded data, the lead researcher provided participants with an emailed summary of the results from the transcripts for their review. Participants had the opportunity to respond and provide feedback on this summary either by email or by phone. This information was used to help shape the thematic analysis, as well as provide a potential measure of authenticity from participants. While only some participants responded, the feedback they provided was positive and confirmatory; none of the participants refuted the information or suggested that changes be made.

Transferability

Transferability is the extent to which the reported experiences and perspectives of participants can extend to other individuals with similar characteristics in similar situations. Researchers explored transferability of data in this study by examining whether the reported communication experiences of patients, caregivers, and physicians in this study during triadic medical interactions were similar across different participant factors. These factors included recruiting participants with a range of severity levels of communication disorders, a range of participant ages, caregivers with different types of relationships to patients, and physicians from different disciplines with range of years of practice. Although the sample size in this study was relatively small, including participants representing these different factors helped to increase the likelihood of transferability of their reported experiences.

CHAPTER THREE: RESULTS

This section includes a summary of demographic data collected from participants, as well as themes and subthemes developed from transcripts of participant interviews. Throughout the remainder of this document, specific participants will be identified by the code number assigned to them when they were enrolled in the study to protect their privacy. Code numbers are a combination of a letter to signify which group participants belongs to ('P' for patients, 'C' for caregivers, and 'D' for physicians, or doctors), and a number based on the order in which they were enrolled in the study. For example, the third patient to be enrolled in the study would be designated 'P3.'

Participant Demographics

A total of 18 individuals participated in face-to-face interviews for this study: six patients, six caregivers, and six physicians. Demographic characteristics for each participant group are described below and summarized in Tables 1-3.

Patients

Of the six patients who participated in this study, half were male and half were female. The mean age was 59.5 years (range 48-77 years). Five of the patients had a medical diagnosis of stroke that resulted in receptive and/or expressive aphasia. The other patient (P4) was diagnosed with primary progressive aphasia (PPA), a degenerative disease without an identified medical etiology resulting in aphasia. With the exception of one patient who exhibited moderate to severe aphasia (P5), all patients exhibited mild to moderate aphasia. Five patients had also been diagnosed with concomitant apraxia of speech and two with short term memory loss. See Appendix P for a complete description of the patients' communication disorder diagnoses. At the

time of the study, all patients were in the chronic stage of their neurologic conditions with mean time post onset of 6.2 years (range 3-10 years). All patients had a history of individual and/or group treatment for their communication disorder, with some still receiving some outpatient treatment services from their local university training clinics at the time of the study. All patients lived in urban or suburban areas of the Pacific Northwest with their family caregivers, with the exception of one (P6) who lived alone. At the time of the study, none of the patients were employed, with three of the patients citing retirement as the reason for their unemployment, and the other three patients citing their medical condition and/or communication disorder as the reason for their unemployment. See Table 1 for a complete summary of demographic information for patients.

During the study, all six patients used verbal communication as their primary method of communication. In addition, all six patients used one or more of the following communication modalities to supplement their speech during interviews: gestures, pointing, writing, drawing, facial expressions, and unintelligible vocalizations. One patient (P5) relied heavily on both gestures and writing to help supplement his verbal communication. Another patient (P6) began using an augmentative and alternative communication (AAC) device (Lingraphica MiniTalk tablet) to supplement her verbal communication during her second interview.

Table 1. Patient Demographics

	Sex	Age	Years Post-Onset	Diagnosis	Reason Unemployed	Previous Occupation
P1	Female	52	3	Aphasia	Medical/Communication [§]	Nurse
P2	Female	48	4	Aphasia	Medical/Communication	Teaching Assistant
P3	Male	62	8	Aphasia	Retired	Surveyor
P4	Male	61	5	PPA [*]	Medical/Communication	Salesman (IT)
P5	Male	77	10	Aphasia	Retired	Lawyer
P6	Male	57	7	Aphasia	Retired	Physician

^{*} = Primary Progressive Aphasia

[§] = Unemployed due to medical condition and/or communication disorder

Caregivers

Two men and four women participated as caregivers. Their mean age was 57.7 years (range 27-74 years). Four of the caregivers were spouses of patients, one was the mother of a patient, and one was an adult son of a patient. Four of the six caregivers were employed during the study. Five of the caregivers were present for either most or all medical interactions between patients and physicians. See Table 2 for a complete summary of demographic information for caregivers.

Table 2. Caregiver Demographics

	Sex	Age	Relation to Patient	Medical Interactions [*]	Communicates for Patient [§]	Routine Care [¶]
C1	Female	74	Mother	100%	50%	Rarely
C2	Male	52	Spouse	≥75%	≥75%	Rarely
C3	Female	59	Spouse	≥75%	50%	Rarely
C4	Female	60	Spouse	100%	25%	Often
C5	Female	74	Spouse	100%	50%	Regularly
C6	Male	27	Son	50%	50%	Rarely

^{*} = How often caregiver is present for medical interactions between patients and physicians

[§] = How often caregiver communicates for patient during medical interactions

[¶] = How often caregiver provides routine physical care for patient (i.e. dressing, bathing, etc.)

Physicians

One of the physicians who participated in this study was male, and the other five were female. Their mean time practicing medicine was 11.5 years (range 2-24 years). Medical specialties of the physicians interviewed included neurology, family medicine, physical medicine and rehabilitation, and palliative care/internal medicine. All of the physicians reported seeing at least 1-2 patients with communication disorders in their practice per week, with half of them seeing at least four of these patients per week. Two of the six physicians (D1 and D2) were nominated by patient and caregiver participant pairs, while the remaining four were recruited through UW Medicine and were not providing care for any patients in this study. Four of the physicians reported receiving some form of general patient-provider communication training during medical school; however, none had received training specific to interacting with patients with communication disorders. See Table 3 for a complete summary of demographic information for physicians who participated in this study.

Table 3. Physician Demographics

	Sex	Specialty	Years Practicing	PCDs Per Week**	PPC Training [§]
P1	Female	Neurology	20	≥4	Yes
P2	Male	Family Medicine	12	1-2	Yes
P3	Female	PM&R*	2	≥4	Yes
P4	Female	Neurology	24	1-2	No
P5	Female	PM&R*	9	≥4	Yes
P6	Female	Palliative Care	2	1-2	No

* = Physical Medicine and Rehabilitation

** = Frequency of patients with communication disorders (PCDs) seen per week by physician

§ = Whether physician has received general patient-provider communication (PPC) training

Themes

Three themes were developed from participant data: ‘Patients and caregivers are a team,’ ‘Patients and caregivers want physicians to “just try,”’ and ‘Physicians want to try, but may not know how.’ Table 4 summarizes the themes and subthemes. The first two themes represent the perspectives of the patients and caregivers, while the third theme reflects the perspectives of the physicians.

Table 4. Summary of Themes and Subthemes

Theme	Subtheme
1. Patients and caregivers are a team.	1.1 The team works together. 1.2 The patient “wants to try.” 1.3 The caregiver helps it “go smoother.” 1.4 Teams can change. 1.5 Teams can sometimes struggle.
2. Patients and caregivers want physicians to “Just try.”	2.1 Communicating with physicians is hard. 2.2 We feel some physicians may not know, or may not try. 2.3 Poor communication can damage the relationship between the team and the physician. 2.4 How communication should be.
3. Physicians want to try, but may not know how.	3.1 Effective communication is our responsibility. 3.2 Communication with patients is hard. 3.3 We rely on caregivers. 3.4 We’re not taught how to do it.

Theme 1: Patients and Caregivers are a Team.

Patients and caregivers often discussed working together to communicate with physicians during medical interactions. In this way, they seemed to form a partnership, or team, when

engaging in communication with physicians and other health care providers. Teams are typically formed to work towards achieving a common goal, with each team member serving a specific function to help reach that goal. Like a team, patients and caregivers described working together to improve communication with physicians during medical interactions, and described the unique roles that each of them may play in helping to achieve that goal. Patients and caregivers regularly used collective pronouns, such as *we*, *us*, and *our*, when discussing their experiences during medical interactions, and some even used the words *team* and *teamwork* to describe their relationship. In addition, patients and caregivers described how their communication roles can change depending on the context of the medical interaction, and how, despite knowing each other for a significant amount of time and having a close relationship, this communication partnership is not always successful.

Subtheme 1.1: The team works together. The main purpose or function of the team, as described by patients and caregivers, was working together to help the patient successfully communicate with the physician. This collaboration usually included either co-constructing a message to communicate to the physician, or decoding information from the physician to help improve the patients' comprehension or recall. When communicating information to physicians, most teams described a scenario in which the patient would attempt to communicate first and then the caregiver would "jump in" (C3) to help modify or clarify the message to make it more understandable for the physician. P3 described the team's co-construction of information during medical interactions, stating, "I think I'll try it, and [if] there's a problem, then she'll do it a little bit too."

To help understand how patients, caregivers, and physicians communicate during medical interactions, some patients were presented with a simple diagram during the interviews and

asked about how communication works during these interactions. This diagram depicted a patient, caregiver, and physician using circles labeled P for patient, C for caregiver, and D for physician (or doctor), and a larger oval around the circles to indicate the context of the interaction. Bidirectional arrows were also drawn between each circle to indicate the potential for communication to occur in either direction between each stakeholder in the interaction (see Figure 3 for a replicated drawing of this diagram).

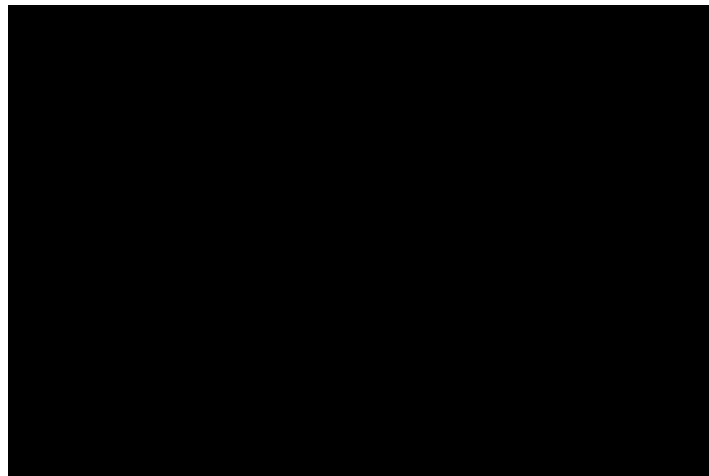


Figure 3. Replication of diagram representing triadic communication during medical interactions presented to P3 and P5 during their individual interviews.

During their individual interviews, both P3 and P5 redrew the diagram, moving the patient and caregiver circles closer together. Both patients indicated this change represented the co-construction of information between themselves and their caregivers that occurs during medical interactions with their physicians. Figure 4 is a replication of the diagram these patients drew.

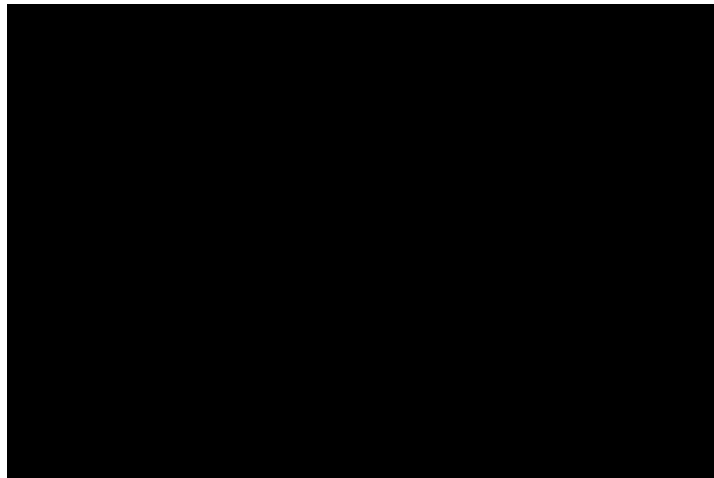


Figure 4. Replication of diagram P3 and P5 drew during their individual interviews to indicate co-construction of information between patient and caregiver during medical interactions.

Even during their joint interviews, patients and caregivers demonstrated how their teams co-construct messages. When patients were asked questions by the interviewer, often they would attempt to answer, and then turn to their caregiver for help if they struggled or wanted to verify that what they said was accurate. One team, P1 and C1, simultaneously described and demonstrated how they work together to co-construct messages in one exchange during their joint interview:

P1: Sometimes if I don't get it (looks at C1), you...

C1: Get it.

P1: Team...uh...teamwork!

For some teams, co-constructing messages for physicians also meant preparing for the medical visit ahead of time. Most of the patients and caregivers described some kind of

conversation that took place before the medical interaction in which they discussed the purpose of the upcoming medical visit, the major pieces of information they wanted to communicate to the physician (i.e. patient's current symptoms), as well as any questions that the patient (or team) may have for the physician. Some teams described having short, informal pre-appointment conversations, while others described having the caregiver take notes or make a written list of questions to ask the physician during the medical interaction. One caregiver (C4) stated, "So we prep. And so, I know what he wants to talk about. But then I let him talk."

Sometimes de-coding the message from the physician also meant reviewing the details of the medical interaction after it was over. Some teams described reviewing information discussed during a medical visit or written information they took away from the visit (i.e. information on diagnoses, treatment options, medications) to either improve the patient's understanding or recall of what happened, or to allow the patient to ask the caregiver clarifying questions about this information that they either did not understand or did not recall from the medical interaction.

Subtheme 1.2: Patients “want to try.” Patients described a variety of communication roles they play during medical interactions. These roles included reporting the reason for a medical visit or symptoms they were experiencing to the physician, being an advocate for themselves for increased independence with communication and inclusion in decision-making about their care, signaling the caregiver when help is needed to communicate, and monitoring conversations between caregivers and physicians for accuracy and completeness. The following section provides a description of patients' communication roles using a selection of key participant quotes. A more comprehensive list of participant quotes describing patients' roles in communication during medical interactions with physicians can be found in Appendix Q.

Reporter. Most patients described their primary role during medical interactions as reporters of their symptoms to physicians. Indicating the severity and location of any pain or discomfort they may be feeling, or any side effects they may be experiencing from medications were examples of things that patients described as being responsible for communicating to physicians.

Even P5, who exhibited moderate-severe expressive aphasia, indicated responsibility for informing his physician of symptoms he was experiencing. When asked what his role or ‘job’ was during a medical interaction, P5 responded by simultaneously making an unintelligible vocalization and gesturing back and forth between himself and the end of the table he was sitting in front of, indicating that it was his job to speak to the physician who would be sitting across from him. When asked what information he was responsible for communicating to the physician, P5 pointed to his left ear (which his caregiver had previously commented had been bothering him lately) and again made an unintelligible vocalization. When asked whether the combination of this gesture and vocalizing meant it was his responsibility to tell the physician his symptoms, P5 responded, “Yeah.”

Self-advocate. Patients also discussed being advocates for themselves during medical interactions. This role seemed to encompass different aspects of communication. Some patients expressed a desire to increase their independence by being the primary communicator interacting with their physician. They wanted the opportunity to try communicating themselves first, and to have their caregivers help them if they struggled or were unable to get their message across. P1 stated, “I want to try...all the time. I want my own life.” Another patient (P3), said, “Well, I guess the thing...as much as I can for me, try to do it.” Advocating for themselves also seemed to include patients letting physicians know the best way to communicate with them up front;

letting physicians know (often with the help of caregivers) which strategies worked well for communication and which did not. Patients also discussed notifying physicians in the moment when they did not understand something, and asking for clarification instead of waiting until later to ask their caregivers. C2 described how his wife (P2) often advocates for herself, stating, “And she says, ‘So, if you can go a bit slow that would be nicer. I may seem fine on the outside, but on the inside my mind is trying to keep up with you.’” Another patient (P4) commented:

If I don’t understand something that he [physician] says, I’m just going to say, ‘What was that? Can you phrase that in a different way, or can you write it down? Or, can we go over this again? I don’t know what you’re saying.’ (P4)

Some teams also expressed the patients’ desire for being informed about their medical condition, as well as being an integral part of the decision-making process regarding their care. When discussing her husband’s need to be informed, C5 stated, “...he wants to be informed. To be informed is very important to him. I suppose some patients just want to be taken care of and made well and pampered.”

When asked if he would still want to be part of the decision-making process about his care, even if he was unable to communicate (which was the case just after his stroke), P3 responded, “Yes. If I can.” He went on to express that patients who are unable to communicate should still be present when decisions are being made about their care and they should try to communicate their thoughts and opinions as much as possible. Regarding her role in decision-

making about her care, P2 commented, “I would say, ‘I would like to talk to you [physician] about it. What you think. And then I will make the decision after.’”

Patients seemed to utilize a variety of strategies to improve their communication during medical interactions with physicians. Patients and caregivers discussed these strategies during their interviews, and patients also demonstrated some of them while answering interview questions. Some common communication strategies included patients pairing their speech with facial expressions or gestures. Writing and drawing were also common strategies that were discussed, as were speaking slowly and asking for more time. For a more comprehensive summary of patients’ communication strategies used during medical interactions with physicians, see Appendix R.

Signaler. Patients and caregivers often described situations or conversations where the patients were struggling to communicate during medical interactions and needed help from their caregivers. When this occurred, they described the patients’ role as signaling the caregiver to “jump in” (C3) and help with the conversation. While there was typically no specific cue or signal that teams described having agreed on prior to entering into medical interactions, patients typically signaled to caregivers for help either by looking at them, gesturing towards them, or verbally asking for help, if able. One caregiver (C3) stated, “If he [P3] feels like he’s not getting through, or can’t completely answer a question that’s been asked, he will turn to me and let me know that it’s my turn to jump in.” Another caregiver (C6) commented, “Sometimes she’ll [P5] look at me and kind of, you know say, ‘Hey’ or give me a look like, ‘Hey, can you answer this for me?’” C1 said, “If you see her [P1] trying to say something, then I try not to fill-in. If she looks at me like, ‘What should I say?’ then I will fill-in.”

Monitor. If caregivers did jump in to help with communication, or if they needed to take over as the primary communicator during medical interactions, teams described the patients' role as then shifting to more of a monitor of the conversation. In this role, patients monitored the accuracy of information being communicated by caregivers to physicians. If caregivers communicated information incorrectly or the information was incomplete, patients would often interject into the conversation to correct information, add additional information, or at least signal to the caregivers that something they said was incorrect or incomplete. C2 stated, "I'll try and ask a question the way I think she wants it. If that doesn't work, I'll look at her and she says, "No. That's not it." C1 commented, "...she will even correct me sometimes if it's not quite what I...what she wanted to say."

Subtheme 1.3: The caregiver helps it “go smoother.” Caregivers also seemed to serve a variety of roles, which focused on helping patients communicate successfully with physicians during medical interactions. Caregiver roles commonly included advocating for the patient, serving as an interpreter for patients and physicians, and monitoring and facilitating the conversation during the medical interaction. The following section provides a description of caregivers' communication roles using a selection of key participant quotes. A more comprehensive list of quotes describing caregivers' roles in communication during medical interactions with physicians can be found in Appendix S.

Advocate. Some participants described the role of a caregiver as an advocate for the patient. Being an advocate included speaking for the patient when the patient was unable to speak for himself or herself, filling in incomplete or missing information to help get the patient's message across, supporting the patient's desire for increased communicative independence by

creating opportunities to communicate for himself or herself, and directing physicians to communicate directly with the patient instead of through the caregiver.

Caregivers seemed to take on the role of advocate early in the patients' stroke recovery, often speaking for patients when the patients had significant difficulties communicating. Patients seemed to depend on caregivers to step in and communicate for them, trusting their caregivers knew them well enough to communicate for them. P2, who was struggling to communicate just after her stroke, referred to her husband (C2) as her "voice." She had told him, "You know my likes and dislikes. I can't articulate them to you, or to the doctor, so you're my voice now."

As patients began recovering their communication skills and communicating more during medical interactions, caregivers' advocated for them by filling in any missing or incomplete information for the patient, or just physically being in the room to support the patient in case they were needed during the medical interaction. When describing his current role as a caregiver during medical interactions, C2 characterized it as being a "safety net" for his wife (P2), implying that she was the primary communicator during her medical interactions with physicians, but that he would be there if she needed him.

Caregivers also advocated for patients by directing physicians' comments and questions to the patient during medical interactions. When physicians would ask caregivers questions or attempt to discuss medical information about the patient, caregivers would often either turn to the patient to ask the same question or provide the same information, or direct the physician to speak directly to the patient. Caregivers unanimously described similar experiences, and discussed how they have directed physicians to speak to the patient as a way to show respect to the patient and address the patients' needs during the interaction. One caregiver (C5) stated,

“You’re the patient. Your appointment. They [physicians] should start with the patient, look them in the eye, and ask them what the issue is.” C4 also commented:

Well, it’s not like they [physicians] don’t talk necessarily to him, but they direct the questions to me. If that happens, I immediately say, “P4, you answer that.” And then if he stumbles, I’ll step in, but it still has to start with him.

When describing how she advocates for her husband (P5), one caregiver (C5) referred to her role as, “protector of the message,” taking responsibility for ensuring the physician received the patient’s intended message. She stated, “And protector...of his answers to make sure that the doctor, or whoever he’s talking to, gets the correct answer.”

Interpreter. Some caregivers served as interpreters for patients during medical interactions. Caregivers described stepping in to interpret what patients were saying when physicians struggled to understand them. They described simplifying or modifying information physicians were trying to communicate to patients, or questions they were trying to ask, in order to improve the patients’ comprehension. C2 stated, “And, um...so I try and simplify it. You know, so it’s easier.” C5 also commented, “Uh, interpreter. You know, if it gets too technical or too fast for him...then I will try to slow it down or simplify it, or explain it compared to something he’s familiar with.”

Monitor. Caregivers also monitored conversations between patients and physicians and helped to facilitate these interactions to improve the success of communication. Sometimes, this meant getting involved in the interaction only to help guide the conversation or keep it on topic but letting the patient continue to be the primary communicator, while other times it meant more

jumping in to take over communication for the patient to ensure the message was understood. C3 described it as being, “the guide on the side” during the medical visit. C4 stated, “And so, and sometimes you let the person...um, express themselves and sometimes you just make it...go smoother.” One caregiver (C6) discussed his facilitating role in this way:

I let them talk or whatever, but I’m kind of there to like “steer the ship” sometimes. You know, because it’s important for her [P6] to talk. But, if there’s anything that she’s having a block with and I know what she’s talking about, or if the doctor asks like a really specific question I know it would be tough for her to answer, then I’ll fill in that information.

Caregivers described using a variety of communication strategies to help improve the success of communication between patients and physicians. They also demonstrated some of these strategies during joint interviews when communicating with patients. Common caregiver strategies included slowing down and simplifying information for patients, providing patients with written or verbal choices, repeating information for patients as needed, and giving patients time to process information and formulate responses to questions. Some caregivers also discussed demonstrating these communication strategies for physicians during medical interactions in the hopes that physicians would also begin using them. For a more comprehensive summary of caregivers’ communication strategies used during medical interactions with physicians, see Appendix T.

Subtheme 1.4: Teams can change. While patient and caregiver teams consisted of spouses, a parent, and an adult child who were family members long before the patients’

communication difficulties began, they gave the impression that this type of communication team formed when the patient began struggling to communicate. They also discussed how, as part of this team, their roles for communication during medical interactions have not been constant, but have instead evolved and changed over time since then. P2 commented that their team “formed over time,” and that it took about two years to feel like their team was functioning optimally. In discussing how their team formed over time, C4 commented, “Well, we’ve been married for 40 years. So, and this [patients’ recovery from stroke] is a slow progression. Right? It’s not a crash course, and not a 3-hour class at the U. It’s a slow progression, and so we have constant communication.”

Patients and caregivers also discussed factors they felt were responsible for changing their communication roles during medical interactions with physicians. These factors included changes in the patient’s communication skills, the context of a given situation, or the complexity of information being communicated.

Changes in patients’ communication skills. As previously discussed, caregivers seemed to take on the primary communicator role right after the stroke in order to advocate for patients’ needs at a time when patients were unable to communicate for themselves. One patient (P6) referred to her communication as “dead” right after her stroke. C1 stated, “Sometimes she [P1] needed something but in those early stages she couldn’t even ask.”

As most of the patients’ communication skills improved post-stroke, the patients took on more responsibility for communication during medical interactions, with caregivers taking more of a secondary, back-up role; thus representing a change in the team’s dynamics. One caregiver (C2) discussed how the roles of the team members changed over time as the patient’s

communication improved, stating, “So, her having a stroke I’ve had to pick up things, and really help her communicate better. Now, I’m finding I just need to be there, next to her.”

C5, however, discussed how although her husband (P5) has made some improvements in his communication skills since his stroke, she typically continues to be the primary communicator during medical interactions as his communication skills remain significantly impaired. She also stated that if she feels P5 can answer a question or provide information the physician is looking for, that she will direct the physician to ask him or will turn to P5 and request that he attempt to provide that information.

The reverse scenario was discussed by one patient and caregiver team, P4 and C4. Diagnosed with PPA in 2008, P4’s communication skills have since begun deteriorating and he is increasingly requiring assistance from his wife and caregiver, C4. Instead of their team dynamics shifting towards supporting the patient in becoming more independent with communication, C4 described having to start taking on more responsibility for helping P4 communicate with physicians during medical interactions as his communication skills have gotten worse. Both team members discussed how P4’s communication difficulties can sometimes take them by surprise, requiring the team to adjust accordingly. During their joint interview, C4 commented, “We get blindsided...all the time. But you know, we go, 'What was that?' and it will be a new step...new phase.” However, like the other caregivers who participated in this study, C4 discussed how she tries to structure P4’s interactions with others (including physicians) to allow him to be as independent and successful as possible with communication.

Situational context. The context surrounding the medical interaction can also cause the roles of team members to shift. Routine medical visits, where the interaction between the patient

and physician is often more relaxed and predictable, may facilitate more opportunities for patients to attempt to be more independent with communication. During routine medical interactions, caregivers seemed more willing to step back and allow patients to be the primary communicator. C4 stated, "I want to be the helper. Out of sight. Right? As much as I can for him, and so I'll just put the conversation back between the two of them, and I'll just pipe up if I need to."

However, during medical interactions that are not routine visits to the physician, such as emergency room (ER) visits, caregivers often took over the lead communicator role. This seemed to be due to both the increased importance placed on the accuracy of information being communicated and the diminished time that was available to allow patients with communication disorders to process information and/or formulate responses to questions. Two caregivers described how ER visits can create communication situations that require them to take over as lead communicator on behalf of the patient. C3 stated, "I think when you're dealing with ER personnel, they don't have a while lotta time to wait for the answers to come from him [P3]..." Similarly, C5 commented, "So, they didn't know him [P5]. They didn't know what he was capable of. So, I pretty much had to be...answer everything for him. 'Cause you know, they depend on speed, and he didn't have time to do that."

Some patients also described the necessity of having the caregiver as the lead communicator during ER visits because of the importance of information being communicated. One patient (P3) compared the relative importance of two of his previous medical interactions, one in an ER during another potential stroke and the other during a regular outpatient medical visit about a problem with his leg. When describing who communicated during the ER visit, P3 commented, "The first one [ER visit]...that was different...you [C3] did, not me. But I mean...it

was important.” When contrasting that interaction with the medical visit for his leg, P3 indicated there was less importance on who took the lead communicator role, stating, “ You know, like now...that one...(points to left lower leg)...really who cares?”

Complexity of information. The complexity of information being discussed during a medical interaction can also create role changes for team members. Some caregivers described patients’ abilities to successfully communicate basic information related to symptoms they were experiencing or to answer basic physician questions such as how the patients were doing or locations and severity levels of pain. However, as information became more complex and abstract, caregivers often discussed taking over as the primary communicator for the team because the level of complexity exceeded the patients’ communication abilities at the time. As one caregiver (C3) stated, "Sometimes, It’s just gotta come from me because it’s too complex for whatever reason."

Subtheme 1.5: Teams can sometimes struggle. According to participants, communication between patients and caregivers around medical interactions does not always go smoothly. Teams can encounter problems ranging from caregivers not knowing what patients are trying to communicate, to jumping in too soon to help patients when patients want to try and communicate for themselves, to preventing patients from initiating communication with physicians. Team members may also disagree about the health care decisions being made for the patient.

Despite having known the patients for years, some caregivers discussed not always knowing what patients were trying to communicate to physicians during medical interactions. Caregivers may have thought they understood the intent of the patient’s message, but in reality

they misunderstood the message. As one caregiver (C1) stated, “sometimes it’s important for her to say what she wants to say because it may not be what I am thinking.” P2 attributed the source of some of the miscommunication between team members to being different people with different perspectives. She stated, “It was very, very, very hard. Because he is a different person. He is a person on his own. I am a person on my own. How will he make...how will he understand what I’m trying to say?”

Sometimes during medical interactions, caregivers would jump in to help patients before the patients needed the help, or at least before they signaled to the caregivers to jump in. This may have been attributed to caregivers being accustomed to being the primary communicator for patients during the early stages of their recovery post-stroke, and not realizing that the patients’ communication skills had improved to the point where they could communicate for themselves. According to one caregiver (C3):

And I was really, you know, take charge right after the stroke. And so, it took me a long time to back off...and where that balance is when it’s good to assert myself. And occasionally I still overstep that bound, and he lets me know.

Other times, caregivers may jump in for the patients because it is easier than allowing the patients to struggle through trying to communicate. One caregiver (C1) discussed why she sometimes jumps in for P1, stating, “Yeah, because I know what she’s trying to say and, so rather than giving her the time to say it, I’ll say it for her.”

Rather than facilitate communication, caregivers may also sometimes prevent patients from initiating communication with physicians. C3 described a situation where P3 had been

having some increased swelling and pain in his leg, and wanted to let his physician know about it by sending him an email or calling him. However, because P3 had an upcoming medical visit a few days later and she did not believe P3's symptoms were serious enough to require immediate medical attention, C3 told him that he should wait and instead talk to the physician face-to-face about it during the medical visit.

Finally, patient and caregiver teams may just simply disagree on which medical decision is best for the patient. Communication of information between the team and the physician may have been successful, with the patient and caregiver understanding the options available to them, but they may just be on opposing sides when it comes to which option to choose. At least half of the patient and caregiver teams described this type of disagreement. When asked how the team handles disagreements about medical decisions, one caregiver (C5) responded that they, "work through them until one gives in." In this way, it seems that the team needs to be open to compromise when making medical decisions during medical interactions.

In summary, theme 1 reflected that patients and caregivers seem to work together as a team communicating with physicians during medical interactions. Both patients and caregivers have specific communication roles on this team which can shift and evolve based on the patients' communication skills and the context in which the interaction takes place. Teams adapt to these changing contexts, and can occasionally experience conflicts within the team that they need to work through.

Theme 2: Patients and Caregivers Want Physicians to "Just Try."

Overall, patients and caregivers reported having mostly positive experiences communicating with physicians during medical interactions. They felt that most physicians did relatively well communicating with patients, and that physicians were doing the best they could

to provide care for the patients. However, they also described some distinct challenges communicating with physicians, including that some physicians did not seem aware of the impact that patients' communication disorders had on medical interactions, and some physicians' appeared unwilling to adjust their communication style to meet the needs of the patients. Patients and caregivers had clear ideas about how communication should be during medical interactions, including changes they thought physicians could make to improve communication with patients.

Subtheme 2.1: Communicating with physicians is hard. Patients and caregivers described some of their experiences communicating with physicians as difficult. Some felt that physicians should have a better idea of how to communicate more effectively with patients with communication disorders. One caregiver (C6) talked about how it is impossible to be a good doctor if communication is not effective. He stated, "There could be the best like actual doctor in the world, but if they can't communicate with the patient then it's kind of useless."

Patients and caregivers seemed to readily acknowledge that a significant amount of the difficulties with communication during medical interactions stemmed from the patient's communication disorder. They described challenges that patients have when trying to communicate what they were thinking and feeling, such as word-retrieval problems, or not remembering what they wanted to say in the moment while talking with the doctor. When asked to describe the hardest thing about talking with physicians, one patient (P6) immediately described her communication limitations, stating, "...um...(nods)...disaster...(chuckles)...I try to work hard, and I just can't do it. I'm struggling here and there..."

However, patients and caregivers also experienced communication difficulties that they felt were more the physicians' responsibility. Some caregivers attributed communication difficulties to the lack of familiarity or history physicians had with patients; that encountering a

new physician who did not know the patient could immediately cause communication challenges. C3 commented, “It was that whole piece of leaving the physician that we had been with for 25 years...I think we didn’t realize what a challenge communication was until we had to start with somebody new.” Another caregiver (C6) stated the following:

It’s just when they’re [doctors] brand new, you know? So, I guess the hardest part is just that having to like explain to them everything for the first time, every time. I don’t know...it’s really an unavoidable problem though, ‘cause they do need to know about what her problem is. It’s just kind of tough.

Patients and caregivers also seemed to feel that physicians should be aware of the ways in which communication disorders could potentially impact patients’ abilities to participate in medical interactions, and to be able to change the how they communicate with these patients to help make communication more successful. C6 stated, “A perfect doctor would be able to know how the person’s feeling, and know how much they have to talk...like what they can say to them so they understand.”

Subtheme 2.2: We feel some physicians may not know, or may not try. Patients and caregivers described experiences in which physicians seemed to be unaware that they need to make changes in how they communicate so that patients with communication disorders can follow the conversation or understand complex medical information. They also discussed instances in which physicians may have recognized the need to change their communication style to improve communication with patients during medical interactions, but did not seem willing to do so.

According to patients and caregivers, speed was a universal reason for communication breakdowns with physicians during medical interactions. They often described how the pace with which physicians conducted medical interactions was too fast, making it difficult for patients to “keep up.” (C6) This sentiment was summarized by C1 who stated, “And they were telling her to do this and do that...but they talk so fast that she didn’t comprehend it.”

Patients and caregivers also felt some physicians seemed to be unaware of the extent to which patients were struggling during medical interactions. This seemed especially true for patients who had recovered a significant amount of their communication skills post-stroke. Two caregivers, C6 and C2, commented:

She’s [P6] like trying to struggle to keep up with them, and I just don’t think they know.

And when I tell them...they will recognize that and repeat themselves, and go slower and things like that...I just don’t think that they know. (C6)

...one doctor said, 'Oh, you [P2] seem to be fine. I know you said you had a stroke, but you seem to converse with me really fine so it didn’t click with me that I needed to slow down...that you’re still suffering with aphasia.' (C2)

Patients and caregivers also described experiences with some physicians who may have been be aware, at least to some extent, that the patients’ communication disorder was impacting their ability to interact with the physician, but who did not change the way they communicated with the patients. These physicians were viewed as being less concerned with how much the patients were understanding, and more on keeping the interaction time to a minimum. One

caregiver (C2) stated, “He’s a young guy...he just wants to process those patients in and out.”

Commenting on a different physician during the same joint interview, P2 stated, “She was really...(makes writing motion on table)...doing as the book and that was it, and whether come in, do the surgery and off you go. I didn’t want that.”

Other physicians were characterized as arrogant, portraying themselves in some way to be superior to patients and caregivers, and maintaining their typical style of communication rather than being willing to adapt their communication to meet the needs of specific patients who were struggling. Patients and caregivers had the following comments regarding physician arrogance and seeming lack of willingness to adapt their communication style:

...his attitude was, ‘I’m the one who knows, and you just have to trust that I know’...other neurologists that we’ve run into are pretty sure that if you’re dealing with the brain that you’re right up there at the left hand of God, if not the right. And there’s a lot of that kind of arrogance. (C3)

She was trying, but she wasn’t...it wasn’t about whether I was getting it. It was about what she was telling me...this is how I do it with all my patients. Right? And it works great. They all love me, they all come back. And, yeah, yeah, yeah...this patient has something I haven’t heard of, but I’m gonna do the same thing because I know that it works. (P4)

...and again I was going to go back to Dr. B. That's why we left her. She was just too rushed, and she didn't seem to have the time...wanting to slow down for P2. And...you know...so we said, 'Okay. I don't think that this doctor is working out.' (C2)

Caregivers also felt some physicians made assumptions about the patients' cognitive skills and ability to participate in discussions and decision-making regarding the patients' care. They were concerned that physicians felt that patients who have communication disorders must also have cognitive problems which would prevent them from being able to make important medical decisions. One caregiver (C5) stated, "They [doctors] think that the stroke survivor has no brain. They think because they can't communicate, they don't think." C3 commented:

I think a lot of people immediately jump to the conclusion when they hear people with speech issues, that somehow there's a cognitive deficit there too...you know, just 'cause they can't get the words out doesn't mean that the words aren't in there.

Subtheme 2.3: Poor communication can damage the relationship between the team and the physician. Communication breakdowns during medical interactions seemed to negatively affect the relationship between patient and caregiver teams and physicians. Poor communication with physicians resulted in a variety of responses from patient and caregiver teams. Teams discussed experiencing feelings of frustration, seeking out second opinions or switching physicians altogether, and the potential for not following-through with physician recommendations for treatment options, such as important medical procedures.

Feelings of frustration. Frustration seemed to be a common outcome of communication breakdowns, and was mentioned during interviews by most patients and caregivers. One patient (P1) stated, “Yes. And very fast! Like, is want to...it’s very fast for me. Now...(slaps her head a couple of times)...a little bit frustrated.” During the same interview, C1 also commented, “And so she [P1] didn’t get it, you know, and so afterwards she was a bit frustrated from that visit.”

Changing physicians. Patients and caregivers also discussed getting second opinions with other physicians or switching physicians altogether if communication did not go well. This was especially true if physicians exhibited any kind of arrogance or indifference to the patients’ struggle with communication. C2 stated, “It’s not worth it. There’s so many oth...this was her [P2] doctor she’d been seeing, so...and she was not too happy with her anyway. So, time to change.” In response to potential arrogance from a physician, P3 commented, “You better knock that stuff...(waving his arm around)...go somewhere else...” One patient (P2) acknowledged that some of her physicians were capable, but did not seem to be the right fit to meet her needs. She stated, “they are good doctors, but not good for me.”

Lack of follow-through on treatment recommendations. Another potential consequence of poor communication with physicians during medical interactions was lack of follow-through by patients on physicians’ treatment recommendations. Some patients and caregivers talked about how communication with physicians could impact their willingness to follow-through on treatment options (i.e. medications, medical procedures). One patient (P2) stated, “I would say three-quarters of the time he was able to understand me...because otherwise I wouldn’t have gone for my surgery, let’s put it that way.”

Subtheme 2.4: How communication should be. Patients and caregivers had clear ideas about how physicians could improve the success of communication during medical interactions

involving patients with communication disorders. They provided advice for practicing physicians, and suggestions for content to include in communication skills training during medical interactions involving these patients. Advice and suggestions included respecting the patients, attempting to understand what the patients are going through, being willing to find out the best way to communicate with the patients, and being prepared to try different communication strategies that may be appropriate. The following section provides a description of advice and suggestions for physicians using a selection of key participant quotes from patients and caregivers. A more comprehensive list of patient and caregiver quotes related to advice and suggestions for physicians can be found in Appendix U.

Respecting the patient. Patient respect seemed to be a central piece of advice for physicians when interacting with patients who struggle to communicate. As one patient (P4) advised physicians, “Respect the whole. Whatever the whole is.” One way patients and caregivers wanted physicians to respect patients was to look at patients and directly address them during interactions, rather than looking and speaking to caregivers about them. One caregiver (C5) stated, “You’re the patient. Your appointment. They should start with the patient, look them in the eye, and ask them what the issue is.” C1 commented, “Cause they [patients] don’t like to be talked about in the 3rd person.”

Respect also seemed to include wanting physicians to acknowledge that the patients are still capable of thinking and making health care decisions despite the presence of a communication disorder. As one caregiver (C5) put it, “Don’t let the wheelchair take away the brain power.” C3 had the following comment about assumptions often made about patients with communication disorders:

I think a lot of people immediately jump to the conclusion when they hear people with speech issues, that somehow there's a cognitive deficit there too...you know, just 'cause they can't get the words out doesn't mean that the words aren't in there.

Understand the patients' perspective. Patients and caregivers also discussed their desire for physicians to try and better understand the patients' perspective; what it is like for the patient to live with a communication disorder. C6 had the following perspective:

You should be able to...when you look at somebody who's having a really tough time, you should feel for them. You should know that there's something more behind it than them just having a problem. Like when you leave, they're still dealing with it 24 hours a day.

Take the time to learn how patients' communicate. Patients and caregivers also discussed wanting physicians to be willing to take the time and learn how best to communicate with patients with communication disorders. This included generally learning how communication disorders can affect medical interactions, as well as learning specifically how to communicate effectively with each of their individual patients who struggle to communicate. One caregiver (C2) stated, "Be patient. Get yourself educated about aphasia. And then learn...understand what the person you are looking after what they can do and cannot do. And they can't tell you. You have to watch." C3 commented, "I think a lot of it has to do with just taking the time...being willing to just sit and listen, and try to figure out what's going on."

Be prepared to try different communication strategies. Patients and caregivers also felt that when communication breaks down during medical interactions and the opportunity arises for physicians to implement different communication strategies, they are often unprepared to do so. Either they are not sure which strategies to use, or they do not have the tools available to them in the room. Physicians should be prepared for these situations to occur, especially if they have frequent interactions with patients who struggle to communicate. One caregiver (C2) stated, “I mean, it’s not rocket science. But having them think, ‘Oh yeah. I should just pull out a piece of paper and draw this, or...’” C3 commented, “...and being aware that there will be other modalities of communication besides just talking. And you know, maybe even providing for that. Making sure that in the exam room there’s a pencil and paper.”

In summary, theme 2 reflected patients’ and caregivers’ views that communication with physicians can be challenging during medical interactions; that some physicians may be unaware of the impact communication disorders can have on patients’ abilities to participate in these interactions, and that some physicians did not change the way they communicate to meet the needs of these patients. Communication breakdowns can also damage the relationship between patient and caregiver teams and physicians, resulting in a variety of outcomes ranging from frustration to the team changing physicians. Finally, patients and caregivers have ideas about how physicians can adapt their communication styles to help improve interactions with patients who struggle to communicate.

Theme 3: Physicians Want to Try, but May Not Know How.

Physicians also discussed their perspectives and experiences with communication during medical interactions involving patients with communication disorders and their caregivers. They talked about the importance of effective communication with these patients, and the role they felt

physicians play in achieving it. Physicians also described the communication challenges they experience with these patients and their caregivers, and the roles physicians expect them each to play in helping to improve communication during medical interactions. Finally, physicians commented on the lack of exposure and training they received related to communicating with these patients, some of the strategies they currently use in their practice to improve communication, and recommendations for what medical students and practicing physicians should know and learn to help them facilitate better communication with these patients.

Subtheme 3.1: Effective communication is our responsibility. Physicians unanimously stated it was part of their role as the health care provider to ensure effective communication and to repair communication breakdowns during medical interactions. One physician (D3) stated, “It rests on me to make sure that I’m facilitating communication and that information that’s being used in decision making for the patient’s care is as accurate and complete as it can be.”

Physicians described their roles during medical interactions in the following ways:

Part of our job is to make sure that information is being communicated and our patients and families have the ability to understand what’s going on. And that we’re communicating that clearly and effectively, and that they have the opportunity to participate and ask questions or clarify things. (D6)

But, I think that’s my primary job is to figure out you know, what is it they [patients] need and not just operate off my list of... “Well, I need to check your blood pressure, and check your cholesterol and...” (chuckle)...you know those sorts of things. (D2)

While physicians took responsibility for ensuring effective communication during medical interactions as part of their role, this responsibility seemed to vary depending on the physicians' individual medical specialties. For example, one neurologist (D1) focused specifically on her responsibility for obtaining an accurate account of the patients' medical history, stating, "...because in neurology, the history is everything." Alternately, a physiatrist (D5) seemed to focus his responsibility for communication more on developing the overall plan of care his patients would receive, stating, "Really in my world, it's [primary responsibility] addressing the rehab needs of the patient." A palliative care physician (D6) discussed yet another area of focus when describing her role as a physician; understanding patients' perspectives related to their condition and what they want to happen with their care. This physician stated:

...so I mostly do palliative care and inpatient consultations, so when we're called, it's usually about issues that are usually critical and also require kind of a great deal of discussion and understanding about what's going on...our evaluations tend to be very long discussions with people, and we really want to get their insight and you know, 'What are your values? What is your life like outside the hospital?' and those sorts of things are really challenging to have...to get to know somebody on a more in-depth level when you have communication difficulties.

Physicians also discussed the importance of trying to understand the nature of the patient's communication disorder and how it affects their ability to communicate during a medical interaction. One physician (D2) stated, "You need to have that sort of assessment of what the patient really...what are their limitations? What aren't their limitations? I think you

have to have that background.” D1 commented, “Try to figure out what’s going on...and what, you know, is happening.”

However, some physicians described their role as more than just understanding how communication disorders can affect their patients’ participation in medical interactions. They were concerned with the social and emotional impact these disorders may have on their patients’ lives, as well as truly understanding the patients’ perspectives during interactions with them to provide the best care possible. They discussed wanting to engage the patient in the interaction, and not making them feel excluded. One physician (D4) stated, “I wanna know what they’re feeling. If they’re feeling pain or anxiety...you know, unfortunately most of what we do really relies on the patient’s perception of what’s going on and without that perception, we can only guess.” D2 commented, “I don’t want him to feel like he’s just a lump in the chair and I’m talking to his wife about everything.” D3 stated the following:

I find it morally burdensome when I can't understand what the patient wants...and I want so much to understand what this person is trying to tell me but I just can't get it and you know I desperately want to have that information so I can treat them in a way that I feel is in their best interest."

Subtheme 3.2: Communication with patients is hard. Physicians discussed the importance of getting the patients’ perspective during medical interactions, and felt their patients play a large role in communicating this perspective to physicians. However, physicians universally described the challenges associated with trying to obtain their patients’ perspectives.

In emphasizing the importance of understanding the patients' perspective, one physician (D3) stated the following:

So, I'm a person that believes that the patient is an integral part of the whole medical exchange...you know? I don't come... I don't think many new physicians at all come from the paternalistic model any more where we think that we just kinda stand up there and make pronouncements and then the patient should comply. So, it's essential to have that piece of the feedback. (D3)

The role of patients. Physicians seemed to characterize the role of patients with communication disorders during medical interactions as they would with any of their other patients; to provide information related to the reason for the medical visit and any symptoms they were experiencing. Additionally, D5 stated the patients' role during a medical visit was, "to decide what he or she wants to be addressed and decide what he or she wants to do with the information and advice that I offer" implying that patients should also be included in decision-making about their care, if not responsible for it. D3 said the following about the role of patients during medical interactions:

...so I rely on the patient to be that expert in hopefully providing me with information about their symptoms and what they're experiencing so that I can, you know treat them...I also need information from them about what they think they're going to

be...what they hope to go on to next after they've been treated. And whether they think they'll tolerate the treatment that I'm proposing to them. Otherwise you know I could come up with some great plan but if they aren't willing to accept it or don't think they can actually carry it out in their lives then we don't have an effective strategy.

One physician (D4) characterized the patients' role in a different way. Instead of providing the information to the physician, the patient was responsible for verifying the information the caregiver provides to the physician about the patient.

Because, as you know, most of the time it's the caregiver who's giving history and telling what the issues are. I guess I try to validate the caregiver's story with the patient if they can kind of affirm yes or no with their thumb up or thumb down. I try to get that information when I examine them to see if there are issues that are related to the complaints that the caregiver describes. So, maybe it's really more of a validation of what I heard from the caregiver. (D4)

Communication challenges. While obtaining the patients' perspectives seemed important to physicians, physicians were quick to characterize their experiences communicating with patients with communication disorders as challenging. One physician (D5) stated, "Well it's definitely a challenge. And I find it can be challenging to maintain communication with the patient rather than relying on the caregiver to provide all the details." D2 commented, "It's one

thing to have an interpreter for my deaf patient but this is a different, much tougher set of patients.” That same physician also went on to say the following:

You know, if it’s you [interviewer], I can pretty quickly tease out what is important to you. What do you want out of that visit? And I sometimes...well depending on patients in general, I ask that question you know, ‘What are you hoping to accomplish in today’s visit?’ just so I don’t miss that. But I can’t always easily get an answer to that question with this group of patients.

According to physicians, time was a primary reason for these interactions being so challenging. Physicians seemed to recognize that patients with communication disorders often require additional time to communicate, but did not often have the time to afford patients this opportunity. D1 stated, “Well, it’s hard because you have a limited amount of time to do things. So, um, I think what I tend to do is talk over patients a lot.” Similarly, other physicians commented on time as a significant barrier to communication with these patients:

I think the first challenge is simply the time required. Those who have communication difficulties we don’t have that sort of...we don’t have that built in cushion as far as scheduling and being able to manage that care. You just have to squeeze whatever their needs are into the time...the usual time that’s allowed. (D2)

Physicians also described the challenge of figuring out their patients' level of cognitive functioning, and how much information their patients with communication disorders actually understood during medical interactions. Accurately assessing their patients' comprehension and cognition seemed to be difficult for physicians. One physician (D6) commented:

I think what ends up being the most challenging part I would say in our situation is actually assessing someone's cog...the communication part is part of it, but that part of the communication where we're actually assessing, "Are they [patients] delirious? Are they understanding my questions? Even if they can or cannot communicate, I think that's the challenging part.

Physicians also struggled with helping patients find a way to reliably and consistently communicate during medical interactions. Lack of consistent, reliable communication from patients seemed to leave physicians unsure about what their patients' wants and needs were, and whether their plan of care was actually addressing those wants and needs. One physician (D5) stated, "I would...try to communicate with the patients and then break down to yes/no and really didn't have a sense talking to the patient whether they could be reliable..." D2 also commented:

Well honestly I think the frustration is feeling like you're not sure that you can truly meet the needs of that patient you don't you can't necessarily figure out what they really want and there are so many different circumstances where you need the patients input to decide whether you're gonna do x, y, or z. If you can't have a clear conversation about that it's pretty tough to know what to do with it.

As with patients and caregivers, struggling to help find consistent and reliable ways for patients to communicate left some physicians feeling frustrated. One physician (D5) stated, "...and also hard is the patient that you just haven't found very effective strategies with. It can be pretty frustrating."

Physicians' response to communication challenges. Physicians seemed to react to these communication challenges and frustrations in different ways. Some physicians said they sometimes resort to guessing what patients are trying to say when they have trouble understanding them, while others chose to give up when communication was unsuccessful. One physician (D4) stated, "Quite frankly, I think what happens is that you just, at some point, give up and decide you don't need all the information, and get the little bits that maybe make a difference." However, physicians mentioned they often rely on the most valuable resource they had available to them when they were struggling to communicate with patients during medical interactions: the caregivers. As one physician (D4) commented, "I usually step back to the most simple of questions...yes/no and try to validate whether those responses are actually correct. And if that breaks down, then I usually look for the caregiver to help me out."

Subtheme 3.3: We rely on caregivers. Physicians often relied on caregivers when they are unable to successfully communicate with patients during medical interactions. For some physicians, caregivers were a lifeline to discovering the needs of the patient. One physician (D1) stated, "Sometimes you just have to...you know, call somebody...people who have seen them or talk to caregivers...if you just really are not getting the information that you need." That same physician also went on to say, "You know, and...without the caregivers, I'm kinda lost."

The role of caregivers. Physicians discussed the different roles they expect caregivers to fill to help improve communication with patients during medical interactions. One of the main

roles that physicians described for caregivers to take on was that of facilitator. They discussed how caregivers make communication easier during medical interactions by helping patients communicate information to physicians, or by relaying information to patients that physicians are unable to successfully communicate themselves. D5 stated:

Caregivers are a huge support. They're a huge help to me as a provider to bring information, to provide information...and they often help facilitate the conversation. Because they tend to know the patient very well and tend to help support the communication if they know what strategies are effective for that patient.

Physicians also described caregivers as advocates, or spokespeople, for patients. Because caregivers know the patients well, they are in a position to provide information about the patients to physicians, especially when patients are not able to communicate for themselves. One physician (D4) stated:

Well, quite frankly, I think they have the most important role. And that's to kind of be the spokesperson for the patient. To make sure that the patient's interests are addressed and that they understand the plan that's laid out for the patient. Because, you know, they have not only the burden of reporting but also implementing any changes that have been made and so it's big deal.

According to physicians, caregivers can also help communication by verifying information patients are communicating to the physician, as well as serve as a “memory bank” (D3) to help patients remember what was discussed during the medical interaction.

...like for patients especially if they have cognitive disorders, which often co-occur with speech and communication difficulties to have the caregiver there because that person also is sort of like secondary memory bank. And you know can kind of serve as a cross check and verify information and make sure that everything gets communicated and recalled and can hopefully also back check a little bit on reporting. (D3)

Finally, physicians discussed caregivers being the person responsible for implementing any plans of care that are agreed on during medical interactions. For example, caregivers may be in charge of scheduling follow-up visits, filling patients’ prescriptions, and helping them remember to take their medications. One physician (D5) commented, “they [caregivers] often help execute whatever the rehab plan is for that patient.”

The team versus individuals. Some physicians seemed to regard the role of caregivers in communication during medical interactions as closely related to that of patients. One physician (D5) referred to patients and caregivers as, “a package deal.” He discussed interactions with patients and caregivers in terms of their combined efforts to communicate. Another physician (D2) commented on the usefulness of watching communication interactions between patients and caregivers, stating,

...intermittently he will be able to generate a very coherent and clear response and at other times it's just a mish-mash what comes out and then I turn to the spouse and she's often able from knowing him well to get at what he is trying to express. So using that interaction between the two of them is extremely valuable to me.

Other physicians seemed to consider patients and caregivers as separate entities, serving distinct functions for communication within a medical interaction. While patients were responsible for communicating their symptoms, caregivers were primarily responsible for being interpreters for patients. One physician (D2) even discussed the potential for caregivers to put patients at risk, and the responsibility physicians have for ensuring caregivers are participating in medical interactions with the patients' best interests in mind:

You need somebody involved to help who's in... directly involved in the care of that patient and you need to be careful about who that is you know. To make sure really you're confident they're gonna operate in the best interest of that patient, because there is a huge risk of patients being taking advantage of in situations.

The drawbacks of relying on caregivers. While often relying on caregivers to help with communication, physicians also seemed to recognize potential pitfalls of having caregivers communicate for patients. Specifically, they were concerned about relying on caregivers who may not know the patients well enough to communicate for them, or getting more of the caregivers' perspectives on the situation than the patients' perspectives. One physician (D2) commented, "If you have a support person who's very astute, very educated, very knowledgeable

about the condition of the patient then it works great. Often you don't have that." D1 stated, "There's... a lot of times where they [caregivers] will... you know, fill everything in for the patients, and it's hard." Similarly, D6 stated:

I think you end up not really truly getting the patient's perspective, even though the surrogates want to do that, and are trying to do that. I think a lot of times they just end up answering for them as opposed to really being the facilitator. They end up being the person to actually provide the information which is not really the goal.

Subtheme 3.4: We're not taught how to do it. While the majority of physicians reported receiving general communication skills training during their medical education and clinical rotations, none had received training specific to facilitating communication with patients with communication disorders. When asked how they learned to interact with these patients, physicians often discussed learning by "trial and error" (D6) during their clinical rotations. One physician (D1) stated, "I think that was through experience in watching my attendings do it." Most physicians seemed to view this as a problem that negatively impacted their current practice. They seemed to suggest that lack of formal training left them feeling deficient in specific skills they needed to successfully interact with patients with communication disorders. Physicians made the following comments in this regard:

...I didn't learn any strategies as to how to go about dealing with these situations. It was pretty much begin to have those experiences as a resident and then step into that as a practicing physician and wing it...and when you hear physicians saying that, 'winging it'

is their way of coping with it most of the time...It's impossible to put everything in four years of medical school training that we would like to put in there. But, I think you're certainly looking at a place where there's a deficit...certainly in my experience. (D2)

...a lot of it is really just trial and error. And sort of thinking out side of the box...trying to be creative. Um, and problem solve...just any way that I can. But no, no there was never any course work or, you know anything where it was said, 'This is how you get around these problems.' So I mean I...(laughs)...I think...it would be quite helpful if there was some formal instruction given in that regard. (D3)

Highlighting the need for medical students and physicians to better understand how communication disorders can affect medical interactions, one physician (D1) described an experience she had while serving as an attending physician in a neurology clinic. She had asked one of her medical students to perform an examination on a patient with aphasia:

I was a neurology attending for a long time...I said to this one medical student...'Patient in 40...whatever...has aphasia, you know...Can you please go do an exam and write a note?' and so I come back and there's no note. 'Why is there no note?' 'Well, the patient wouldn't talk to me.' I was just so...amazed by that and I don't know if that's just complete lack of common sense or people are just unexposed...that they really don't get it. But in the neurology world, most people won't talk to us and we still have to actually, you know, figure out what's going on.

Physicians' communication strategies. Physicians discussed “trying their best...” (D1) to find strategies to help patients communicate. Although having received no formal training, physicians described a variety of strategies they have tried to help improve communication with their patients with communication disorders. Common strategies physicians tried included slowing down, asking yes or no questions, writing down information, and using visual cues such as gestures. For a more comprehensive list of physicians' communication strategies, see Appendix V.

Physicians reported having varying success with the use of these communication strategies. They felt they were sometimes able to obtain the information from patients and caregivers they needed to help develop and implement a plan of care for patients, but other times they were not. One physician (D2) spoke about how he communicates successfully with one of his patients with a fluency disorder:

I have a patient with who's a severe stutterer...I know to put him at ease and to help him be able to speak. If my body language is saying 'come on hurry up,' it's not gonna go well. I need to not interrupt. I need to let him get his questions out and I find with his particular problem if I just chill out and give him time and make it a relaxing interaction then he does fine. But I can pretty quickly make it go the opposite direction if I don't take some care with that. So it's really is a matter of adapting the situation.

According to physicians, getting to know patients with communication disorders better can help with communication. Specifically, becoming more familiar with how patients

communicate, including strategies that have been previously successful for patients, is often a helpful strategy for physicians. One physician (D2) commented:

So I've gotten to know him [patient] very well over the past two years. You have to know those patients well. If you're in a clinic where you might see the patient this time and your partner sees him the next time and a third person sees him the next time...if you have that sort of fragmented care, it's all gonna fall apart. You really need to build a relationship with that family.

Two physicians (D5 and D6) also described a strategy they sometimes employ, which involves having a speech-language pathologist assist them in communicating with their patients with communication disorders:

And I have a speech pathologist who sees patients with me. We do a round robin style format in that clinic. I had a patient with bulbar onset ALS who had lost his ability to use his adaptive communication device. He had a DynaVox but no longer had the capacity to use it. And...the speech pathologist actually came into see the patient just before I...or alongside with me in clinic and helped to establish a method to communicate with the patient with blinks. And with that we were able to coordinate care better. We actually admitted the patient to have some really serious end of life discussions and um, were able to com...to transition the patient home to hospice. (D5)

But, if we do feel like the patient is somewhat oriented in being able to follow the conversation, then I'll have that kind of conversation with the speech therapist there, and we'll actually just do it together. So they're helping me with the communication piece, and I can focus on what I'm actually trying to accomplish...not being distracted on how to get that information across. (D6)

One strategy that seemed to save some time during face-to-face medical interactions was the use of email and phone calls outside of these interactions to keep patients and caregivers in touch with their physicians on a more regular basis. D2 discussed how he has used both of these strategies to stay in contact with some of his patients between regular visits:

Here, we have a secure email system. So, that allows for a lot of communication outside of patient visits. We use that a lot. We schedule telephone encounters rather than doing everything with patients in the office visits, so that allows me to even schedule communication time with...whether it's the patient or a family member...whoever that's involved. But, figuring out how to use some of the time outside of the clinic to do that communicating.

However, communication strategies are not always successful. One physician (D3) described an experience she had trying to utilize yes or no questions with a patient with aphasia, which was not successful:

The yes/no thing has worked well with many patients. But I was trying to use the yes/no thing with a patient once, who I began to realize over time seemed like one of her kind of conceptual difficulties with her speech construction was that she had problems with synonym/antonym pairs. And so, 'yes' and 'no' was actually...she...and left and right... you know opposites were a source of confusion for her. And so she would answer 'yes' when she could have meant 'no.' Or she would answer 'right' when she...so she had these kind of word pair issues (chuckles)...So, it was a horrible strategy to use for her...and so then I relied more on her non-verbal cues once I realized that was the case.

Formal communication skills training. Physicians discussed the potential benefits of receiving training to improve their ability to facilitate communication with patients with communication disorders. Some even talked about specific areas of training they might find useful in their practice. This section summarizes some of the ideas or topics that physicians suggested should be part of formal communication skills training with these patients.

Some physicians discussed being more educated about communication disorders would help physicians facilitate communication with these patients. D1 felt that future physicians need to have a better understanding of the basic definitions and characteristics of communication disorders, such as aphasia:

Well, I think they [medical students] definitely need to understand the different types of abnormal communication. So, I think they have to understand what really is aphasia? You know, what does receptive aphasia look like? What does expressive aphasia look like? You know, what does a transcortical aphasia look like? What does anomia or

dysnomia look like? What does apraxia look like? I think they really need to know this stuff. Because otherwise they think that patients are...you know, not cooperative or demented when they're really not.

Other physicians discussed the need for medical students and practicing physicians to learn and implement specific communication strategies with patients with communication disorders. One physician (D5) stated, "Some basic tools for the non-speech pathologist would be wonderful...so basic tools that an MD could implement in a very short time period to facilitate communication with a patient with a communication disorder would be wonderful." D3 commented, "So it'd be nice to maybe have like one lecture that would be about that. Sort of like here's the tricks and tools and things you know that might be applicable." D4 described some basic strategies that medical students and practicing physicians should use with these patients, and that current residents may not be aware of their benefits:

Well, it should be very obvious things. This actually came to light 'cause I was on clinical service and our junior resident spoke very quickly, in very large sentences. You know, these are brain-injured people. Couple words, very slowly. So I think that one clear message is to use minimum amount of words needed to get your point across, to ask questions. Say it very slowly. Be patient because often time there's a response coming, you just need to wait for it. And I think patience and creativity are really...the other thing is to learn to how to get a response, maybe not a verbal response, the kind of response that might give you the information you need.

Physicians also suggested that physicians should be better able to evaluate patients' cognitive-communication skills. D6 addressed physicians' needs for more advanced assessment skills in this area:

So, I would say that's the part that I feel we [doctors] need the most help with. What are the skills to first just be able to understand? Assess somebody's cognition, and then at the different levels? You know, you start at like egocentric, and then non-egocentric questions. I think providers...we're used to doing orientation questions. 'Do you know what the date is? Do you know where you are?' And that's very basic. We [doctors] need to know what the skills are to be able to do the next level from that.

More immediately than during formal training, one physician (D1) mentioned that she would benefit from patients or caregivers describing any communication strategies that have already been established and are working to help patients communicate at the start of the medical interaction itself. She stated, "That would be very helpful...if they came in and said, 'You know she really doesn't do good. You have to talk really slow, or really loud, or write it down, or...'"

In summary, theme 3 reflects the physicians' perspectives regarding their experiences with communication during medical interactions involving patients with communication disorders and their caregivers. Physicians felt responsible for ensuring effective communication with these patients, but the focus of this communication seemed to vary across medical specialties. Physicians described communication with these patients as difficult, and although obtaining the patients' perspective was important to them, physicians acknowledged that they tended to rely on caregivers when communication with patients was not successful. Although

they had not received formal communication skills training with patients who struggle to communicate, physicians talked about strategies they have used to interact with these patients, often with varying degrees of success. Physicians talked about the need for formal training with these patients, and suggested some content areas that should be included in this training.

CHAPTER FOUR: DISCUSSION

The purpose of this study was to explore the perspectives of patients with communication disorders, their family caregivers, and physicians related to triadic communication during medical interactions. In addition, this study was designed to examine the relevance and appropriateness of CAT in analyzing communication during these medical interactions. Eighteen individuals - six patients, six caregiver, and six physicians - participated in semi-structured interviews as part of this study. This section includes a discussion of how and why researchers attempted to help patients with communication disorders provide their thoughts and perspectives during interviews, a review of the main ideas and perspectives participants discussed, and an analysis of these ideas in the context of existing research. Study limitations are also examined, as well as implications for research and clinical practice.

Meeting the Challenges of Interviewing Patients with Communication Disorders

Interviewing patients with communication disorders as part of this study presented a unique challenge. Communication disorders can interfere with an individual's ability to respond to interview questions, making it difficult for researchers to obtain his or her thoughts and perspectives. Thus, researchers modified the methods used in typical semi-structured qualitative interviews to interview patients in this study, providing these patients with an opportunity to successfully respond to interview questions.

Strategies for Interviewing Patients with Communication Disorders

Researchers utilized a variety of strategies to conduct interviews with patients with communication disorders. First, while all interviews were audio recorded to later be transcribed, patient interviews were also video recorded. Some patients who struggled verbally respond to

interview questions were able to provide nonverbal responses, such as gestures, facial expressions or written information, to help answer to interview questions. Video recording patient interviews allowed researchers the ability to transcribe patients' responses in whichever form (verbal and/or nonverbal) they chose to provide them. In addition, researchers used a variety of support strategies to help patients successfully respond to interview questions. These strategies included establishing a consistent, reliable method of communication with each patient before the interview began, simplifying interview questions to improve patients' understanding of what as being asked, making questions less open-ended (i.e. yes/no questions, multiple choice questions) as needed, providing more time for patients to process information and formulate responses, and writing down key words for patients to refer to when responding to questions. Use of these support strategies often resulted in the co-construction of patients' responses to interview questions.

Rationale for Joint and Individual Interviews

Interviewing patients and their family caregivers jointly and then later individually provided unique information related to communication with physicians during medical interactions. The purpose of jointly interviewing patients and caregivers was to gather data related to their collective experiences communicating with physicians during medical interactions. It also provided an opportunity for the researchers to directly observe communication interactions between patients and caregivers, and for patients to get assistance from caregivers to co-construct answers to interview questions. If interviews were only conducted individually during this study, data may have contained a less comprehensive perspective on how patients and caregivers work together to facilitate improved communication during medical interactions with physicians. Following-up with individual interviews then

allowed patients and caregivers the opportunity to respond freely to interview questions and discuss experiences and perspectives related to communication during medical interactions in their own words.

Rationale for Co-Constructing Patients' Perspectives

The presence of communication disorders often made it difficult for patients to provide answers in their own words, and they typically required assistance from either caregivers or interviewers to express themselves. Researchers did their best to ensure co-constructed answers were consistent with the patients' perspectives. This was achieved by double-checking information with patients, and reiterating their answers to have them verify them using a consistent and reliable method of communication that had been established before the interview began.

Review of Participants' Main Ideas and Perspectives

Patients, caregivers, and physicians provided interesting and thoughtful insight and perspectives on their experiences with communication during medical interactions. These ideas and perspectives seemed to be represented by three main themes. Results from this study are summarized in the following section.

First, patients and caregivers seem to function as a team during medical interactions. Like a team, patients and caregivers share a common goal of improving communication between patients and physicians, and each team member has distinct roles they play in an effort to contribute to this goal. Patients seem to have a primary role of reporting the purpose of the medical visit and any symptoms they are experiencing. They are also responsible for advocating for themselves, often signaling caregivers when they are struggling to communicate and need

help, as well as monitoring communication between caregivers and physicians to clarify or correct information as needed. Caregivers have the primary responsibility of monitoring and helping facilitate communication between patients and physicians; to speak on behalf of patients when they are unable to communicate themselves, to interpret information patients are trying to express to help physicians understand, or vice versa. Caregivers also serve as advocates for patients, keeping them involved in the medical interaction and included in decisions about their care. The roles patients and caregivers serve during medical interactions can also change based on the context and circumstances of the interaction. Factors such as the patients' communication skills changing over time, the type of medical interaction (i.e. routine medical visit versus an Emergency Room visit), and the time allotted for this interaction can cause patients and caregivers to shift their roles to improve or maintain communication with physicians during that interaction. Finally, although patients and caregivers work as a team, they do not always function successfully as such. They sometimes struggle in their communication with one another, or simply may not agree on decisions regarding the patients' care.

Second, patients and caregivers want physicians to "just try" to communicate with patients during medical interactions. Overall, patients and caregivers had positive experiences communicating with physicians. However, interacting with physicians was also difficult at times. Patients and caregivers felt that some physicians seemed unaware of the impact that communication disorders had on the patients' abilities to participate in medical interactions. They also believed that some physicians did not change their communication when patients were not able to understand them or follow the conversation. Patients and caregivers felt physicians should be willing to take the time to educate themselves on the patients' communication disorders, learn how these disorders have affected individual patients, and what strategies they

can use to try to improve communication. They also felt physicians should be willing to take the time and try using these different communication strategies to help improve communication during medical interactions.

Third, physicians seemed to recognize the importance of effective communication, but did not always know the best way to help improve it when interacting with patients with communication disorders and their caregivers. Physicians acknowledged the importance of understanding the patients' perspective during medical interactions and their role in obtaining this perspective, but they often struggled to accomplish this task when patients exhibit communication disorders. Consequently, they rely on caregivers to facilitate communication with patients or have them provide information about patients, acknowledging that this may not be the ideal way to obtain the patients' perspective. Physicians recognized the value and importance of receiving communication skills training related to patients with communication disorders, and suggested some possible areas of content for this training. These areas included information on the different characteristics of communication disorders and how they can potentially impact communication, learning different communication strategies, and understanding appropriate times to use them to help improve communication with these patients during medical interactions.

Communication during Medical Interactions

Patients with communication disorders who participated in this study frequently had family caregivers present to help with communication during medical interactions, creating triadic interactions with physicians. However, patients and caregivers described working together in a partnership, or team, with a common goal of helping patients and physicians effectively

communicate with one another. Thus, although there were three people in the room during these medical interactions, patients and caregivers seemed to function as more of a single unit, creating a communication dynamic more like that of a dyad than a triad. In fact, some patients and caregivers described situations in which caregivers were speaking on behalf of patients (who were unable to communicate), also essentially creating a dyadic communication situation.

A 2012 study by Karnielli-Miller and colleagues also found that medical interactions involving patients, companions (caregivers), and physicians functioned more like communication dyads than triads, but for a different reason. In this study, rather than patients and companions working together to function as a team, communication triads typically functioned more like dyads because either the patients or companions were more dominant in the interaction with the physician. This dominance marginalized the partners' role in communication, effectively excluding them from the interaction.

Results of the current study also suggested that caregivers frequently seem to have a significant effect on communication during medical interactions. Patients and caregivers discussed how caregivers often helped facilitate communication during interactions with physicians, and how sometimes they needed to speak on behalf of the patients when patients were not able to communicate for themselves. Typically, caregivers were helpful in facilitating improved communication. However, other times they jumped in too soon before giving the patients a chance to communicate, or did not understand what the patient was trying to communicate and got the message wrong. These experiences were consistent with the results of current research. In 2013, Laidsaar-Powell and colleagues conducted a systematic review exploring triadic communication during medical interactions involving patients, companions (caregivers), and physicians. Results of this study indicated that while caregivers were often

perceived as helpful and increased patient satisfaction with communication during these interactions, the addition of a third person created some communication challenges to the interaction between patients and physicians. Specifically, the roles of companions in communication were unclear and these individuals often seemed confused as to what their responsibilities were during the interaction.

Some physicians in the current study seemed to address patients and caregivers as separate individuals with specific communication roles, while other physicians seemed to recognize the communication partnership and common goal of improving communication that patients and caregivers shared. Physicians who viewed patients and caregivers as having distinct roles in communication often discussed the patients' role as providing information related to their symptoms, while the caregivers seemed to serve as interpreters to help physicians understand what patients were trying to communicate. However, patients and caregivers were referred to by one physician as a "package deal," and some physicians discussed benefitting from watching communication between patients and caregivers as a model of what they should be doing. Physicians recognized that these caregivers knew the patients well, and were advocating for the patients by facilitating communication for them.

In summary, medical interactions involving patients with communication disorders typically involve three people. However, both the results of this study and current research suggest that these interactions often function more like dyadic than triadic conversations. Caregivers can significantly impact medical interactions, either helping to facilitate better communication or actually hindering it. Some physicians view patients and caregivers as individuals with distinct communication roles, while others may see them functioning together as a communication team and interact with them as such.

Models of Communication for Medical Interactions

Results of this study suggest that Communication Accommodation Theory seems to adequately represent the process of communication during medical interactions involving patients with communication disorders, their family caregivers, and physicians. In addition, results have helped to inform a working model of CAT to represent communication during these medical interactions. This working model has evolved over the course of this study from the previous revised model (depicted in Figure 2) that was proposed before the study began. Analyzing the perspectives of the participants, as well as specific feedback from two patients, were responsible for this evolution.

Participants discussed the need for physicians to change the way they communicate to improve the patients' understanding of information during medical interactions. While participants seemed to agree that physicians needed to make accommodations to their communication to meet the needs of their patients, this did not seem to consistently occur. According to the results of this study, examples of physician and caregiver over-accommodation were more typical; physicians would address the caregivers instead of the patients, and caregivers would either speak for the patients or take over communication too soon when it was not necessary. Physician over-accommodation towards patients with disabilities has been shown in recent research to be a common occurrence in medical interactions (Bylund et al., 2012). Instances of physician under-accommodation were also discussed by participants in the current study, where physicians continued to use their typical communication style without adapting to meet the patients' needs, even when patients were struggling to understand or follow the conversation. This was described less often by study participants.

Patients and caregivers seemed to attribute physician over- or under-accommodation to different factors. Patients and caregivers discussed that some physicians seemed to be unaware of their patients' struggling to communicate during medical interactions, and that some physicians simply did not change the way they communicated to help the patients. Patients and caregivers also felt that some physicians made assumptions about the cognitive abilities of patients based on their diminished ability to communicate. Physicians, on the other hand, seemed to recognize the need to make communication more effective with patients, but felt they were often unsure which communication strategies may be the most useful for their patients.

Context of Interactions

According to CAT, the context in which medical interactions take place can impact the effectiveness of communication. As previously discussed, context can be the physical environment in which the interaction takes place, or the situational context (i.e. reason for the interaction, time constraints, and so on). It can also include internal factors, such as the beliefs or attitudes of the individuals involved in the interaction. Participants in this study acknowledged and discussed the effects of context on communication during medical interactions. However, they tended to focus on discussing the situational context of the interaction rather than the physical environment in which it occurred. Time constraints, for example, were mentioned by many participants as a factor in the effectiveness of communication. Limited time during medical interactions not only shifted the roles of patients and caregivers, often putting caregivers in the lead communicator role, but also prevented physicians from allowing patients the time they needed to process information or formulate responses to questions. The type of interaction was another important contextual factor in communication during medical interactions. The communication context of a routine medical visit was significantly different from that of an ER

visit, where the pace of communication was quicker and the importance of accurately communicating information was high. During routine medical visits, patients were more often given an opportunity to communicate for themselves. During ER visits, caregivers tended to take on a more significant role in communication, or communicate for the patients.

Developing a model of CAT

Results of this study have informed the development of a working CAT model for communication during medical interactions involving patients with communication disorders. The original proposed CAT model, shown in Figure 2, depicts patients, caregivers, and physicians as three distinct communicators equidistantly separated in the diagram. However, as discussed in the previous section, results of this study suggested that patients and caregivers seem to work together as a team to co-construct messages for physicians and decode the meaning of information physicians communicate to them. Further, P3 and P5 also provided similar feedback when they re-drew a model of communication during medical interactions with the patient and caregiver circles closer together. Figure 5 represents the revised version of this model based on the results of this study. In this figure, the patient and caregiver circles are partially overlapping, with the overlapping space labeled *team* which represents their functioning together to communicate as a team. Thus, while they are individual people, they also function together as more of a cohesive unit to communicate during medical interactions. Both under- and over-accommodation are also represented in this model, similar to the model in Figure 2 that was proposed before this study began.

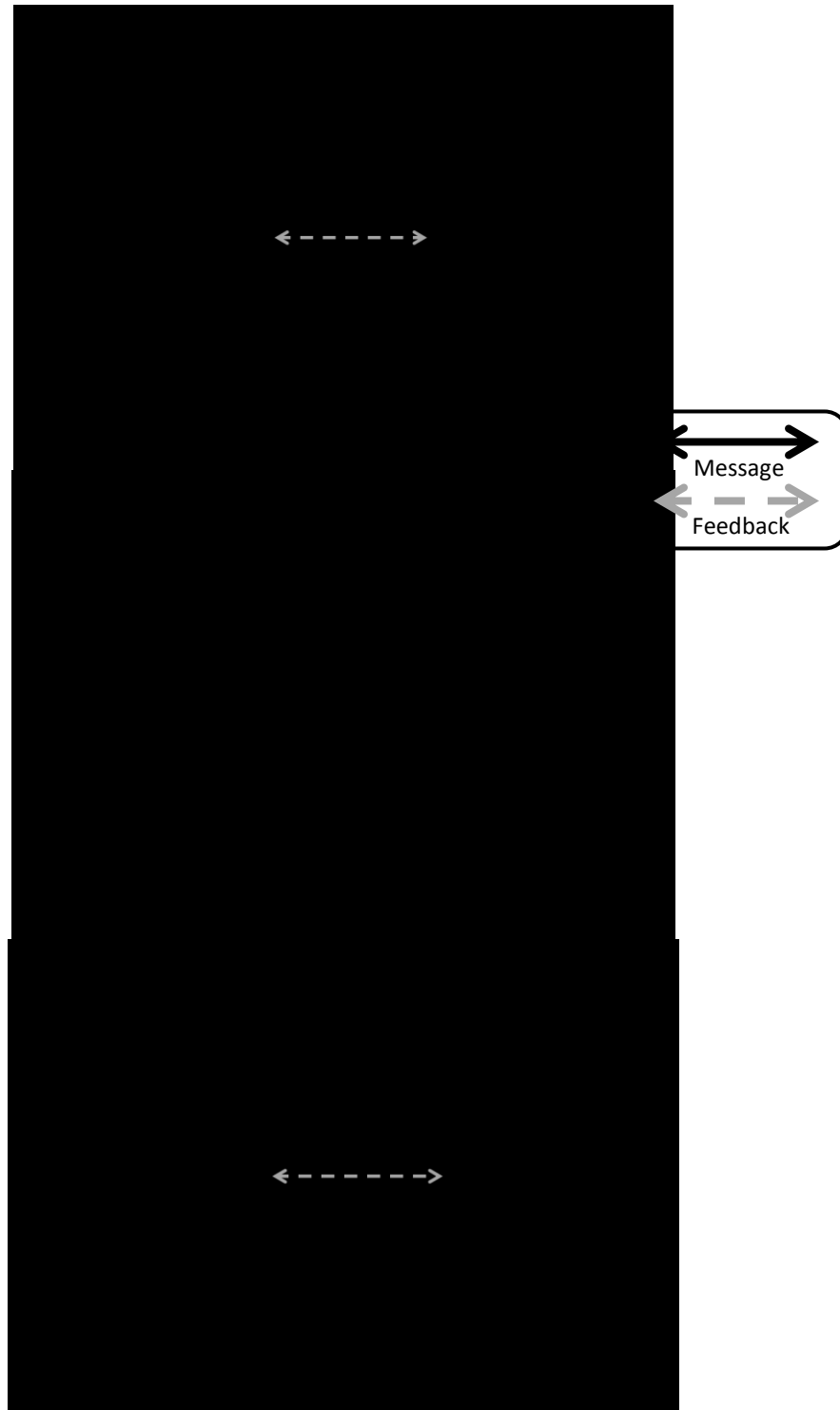


Figure 5. Revised model of CAT for communication representing patients with communication disorders and caregivers functioning as a team to communicate with physicians. Accommodation is depicted by the message (solid arrow) remaining between the patient and physician while feedback is used (dotted arrow) to influence changes in communication. Under-accommodation is depicted by the message remaining between the physician and patient while no feedback is being used by the physician (elimination of dotted arrows) to influence changes in communication. Over-accommodation is depicted by the message occurring between the physician and caregiver, bypassing the patient, despite feedback indicating the patient may be able to participate in the interaction.

Study Limitations

Limitations of this study primarily centered around recruiting and interviewing methodologies. Limitations included recruiting a convenience sample of participants from a limited range of resources and within a single geographical location, patients who shared a common communication disorder and who were only in the chronic stages of living with their condition, and patient and caregiver pairs who represented a limited variety of familial relationships and who reported primarily positive communication experiences with physicians. Also, while helping patients co-construct their responses to interview questions was necessary to allow them to participate in this study, it was seen as a limitation. Finally, having a limited amount of time to interview physicians prohibited the opportunity to explore their perspectives in-depth.

Recruiting Limitations

Participants recruited for this study were a convenience sample of the population from a small geographical location in the Pacific Northwest. Thus, it is possible that their perspectives and experiences regarding communication during medical interactions do not represent those of individuals who live outside this area. In addition, all patients and caregivers in this study had been enrolled in or exposed to speech therapy services at some point since the patients were diagnosed with communication disorders. Exposure to therapy gave these participants a potential advantage for achieving successful communication during medical interactions over patients and caregivers who may have not yet had this opportunity for therapy.

While their communication disorders ranged in severity, all patients had been diagnosed with aphasia. Originally, patients recruited for this study were to represent a variety of communication disorder types; however, most of the patients who contacted the lead researcher

about participating in the study were from the UW Aphasia Registry and Repository. All patients were also in the chronic stages of their recovery, with the exception of P4 who had a diagnosis of PPA, a degenerative communication disorder. Thus, patients who were in the more acute stages of adjusting to having a communication disorder were not represented as part of this study. It is possible patients who are just beginning to struggle with communication may have different experiences and perspectives to share regarding their interactions with physicians.

The majority of patient and caregiver pairs recruited for this study were spouses. Exceptions were one pair consisting of a mother who was a caregiver for her adult daughter, and one pair including an adult son who was a caregiver for his mother. Thus, limited data was available to compare, as well as to differentiate, the communication experiences of patients and caregivers who are spouses versus those who have a different familial relationship. It is possible that the familial relationship between patients and caregivers can affect their communication experiences during medical interactions with physicians, but more data is needed to make this assertion.

Overall, patient and caregiver pairs reported positive experiences communicating with physicians during medical interactions. While it is important to explore their perspectives and learn why these experiences were positive and how communication worked well, these positive experiences are likely not universal for all patients with communication disorders and their caregivers. Collecting data from individuals who did not have such positive experiences would also be helpful in learning about the process of communication during medical interactions, how communication breakdowns can occur, and the perspectives of individuals who have experienced these breakdowns.

Methodological Interviewing Limitations

Patients recruited for this study had difficulty communicating their experiences and perspectives, especially when attempting to answer open-ended semi-structured interview questions. Patients often needed assistance from interviewers and caregivers (if present) to either understand the interview questions, or express themselves when answering questions during interviews. Because patients' answers to interview questions were often co-constructed, it is possible that their answers were not truly representative of patients' perspectives, but instead influenced by the person who was involved in the co-construction. Thus, while it was necessary to help patients' co-construct their answers to interview questions, this was not ideal to obtain the patients' perspectives according to traditional qualitative methodology. However, helping patients co-construct their responses to interview questions was also viewed as a strength of this study, as it helped facilitate the inclusion of these individuals in qualitative research who may not have otherwise been able to participate. During this study, interviewers made every effort to reiterate any co-constructed answers to patients for verification to ensure they were consistent with the patients' perspectives.

A relatively small sample of individuals was recruited for each participant group in this study. However, during interviews a large number of ideas and perspectives seemed to be repeated across patient and caregiver pairs and physicians, respectively. Thus, saturation was achieved with the recruited participant sample.

Physician participants had busy work schedules, leaving them with limited time to be interviewed for this study. Physician interviews averaged approximately 30 minutes, compared with an average of 60 minutes for patient and caregiver interviews. Restrictive time limits made it difficult to conduct in-depth interviews to explore physicians' perspectives and experiences

interacting with patients with communication disorders and their family caregivers. Thus, the amount of information collected during physician interviews was determined more by time limits than by exhausting all interview questions. While there seemed to be sufficient time to gather enough information to develop a theme and subthemes that capture the physicians' perspectives on communication during medical interactions involving patients with communication disorders, it is possible it may not fully represent the physicians' viewpoints. Having more time to further explore some of the information physicians provided may have been beneficial in helping to better represent their viewpoints.

While interviewing physicians who were referred by patient and caregiver participants (D1 and D2) provided some insight into actual communication experiences that had occurred with these patients and caregivers, it also potentially served as a limitation of the study. It is possible that these physicians withheld information about their perspectives or experiences to protect the confidentiality of the patients and caregivers involved, and/or to preserve the relationship they had with these patients and caregivers - especially if their experiences or perspectives were negative.

Implications for Research and Clinical Practice

Results of the current study have significant implications for future research and clinical practice involving patients with communication disorders for both physicians and speech-language pathologists. The following section summarizes key research and clinical implications identified from the results of this study in these areas.

Implications for Future Research

Results of this study provide some insight into the perspectives and experiences of patients with communication disorders, their caregivers, and physicians regarding communication during medical interactions. While it adds to the existing research in this area, it also highlights how little is known about these perspectives and experiences. Thus, the results of this study also have implications for future research in this area. Areas of future research include (1) continuing to explore the perspectives and experiences of patients with communication disorders, their caregivers, and physicians with communication during medical interactions, (2) analyzing actual medical interactions involving these patients, their caregivers, and physicians, (3) continuing to examine of CAT as a viable theory for explaining and predicting communication during medical interactions as well as continuing to develop a model of CAT to represent these interactions, and (4) effectively providing communication skills training related to communication with patients with communication disorders to physicians. Finally, results of this study have implications for recruiting of individuals with communication disorders as participants in qualitative research.

Exploring perspectives on communication during medical interactions. Further research is needed to continue exploring the perspectives of patients with communication disorders, their family caregivers, and physicians regarding communication during medical interactions. Research should include patients with aphasia as well as a variety of other communication disorders, such as dysarthria and apraxia of speech, and with differing severity levels. It is possible that the experiences of these patients and their caregivers may be different than those who participated in this study. Future research should also include patients with communication disorders who are in the more acute stage of recovery, as results from this study

seemed to indicate that communication in the acute stage tends to be more difficult during medical interactions. Additionally, research should focus on exploring the perspectives of patients and caregivers representing a variety of familial relationships, including spouses, parents, adult children, and other family members who may be providing care for patients. Only then can comparisons be made within and across groups of patients and caregivers with different relationships.

Research should also be conducted involving patients and caregivers who have had less positive experiences communicating with physicians during medical interactions than the participants in this study. It is possible that these individuals would have different perspectives on this common life activity, as well as different advice for physicians on ways they can help improve communication. Finally, more in-depth research should be conducted exploring the perspectives and experiences of physicians from a variety of specialties and with a range of years of experience in their practices. Physicians' experiences interacting with patients who struggle to communicate could differ based on factors such as their medical specialty, years they have been practicing, or the (lack of) communication skills training they received when they were in medical school.

Analyzing actual medical interactions. To better understand the dynamics of communication during medical interactions involving patients with communication disorders, future research should also involve recording and analyzing actual medical interactions involving these patients, their caregivers, and physicians. Techniques such as conversational analysis have been used successfully to understand conversational interactions between speakers with severe dysarthria and communication partners (Bloch & Wilkinson, 2009). Examining communication during real medical interactions can provide some insight into how communication actually

breaks down and is repaired instead of relying on the participants' ability to recall what happened during previous interactions. It can also provide demonstrations of effective communication between patients with communication disorders and their physicians when it occurs.

Using CAT to explain communication during medical interactions. Results from this study have offered a better understanding of how CAT can be applied in the context of medical interactions involving patients with communication disorders, their caregivers and physicians. It has provided some initial awareness regarding how patients with communication disorders can become vulnerable and lost during medical interactions, when caregivers and physicians do not make the necessary accommodations to help them improve their understanding and successfully express their opinions and perspectives. It has also provided some initial insight into the frequency and ease with which people can inadvertently change and simplify their communication when patients may not need it, creating over-accommodation.

Results of this study have informed a working model of CAT for medical interactions involving these patients, providing a visual representation of how communication may potentially occur. However, the amount of research regarding the application of CAT to patients with communication disorders during medical interactions is woefully inadequate to posit any concrete conclusions about its usefulness. Further research is needed to explore CAT in this context to determine how it may be used to both explain communication involving patients with communication disorders during medical interactions, as well as help identify areas of intervention that can be addressed to help reduce over- and under-accommodation and improve overall communication with these patients.

Providing communication skills training for physicians. Results of this study also reinforce the need for research evaluating the effectiveness of communication skills training related to communication with patients with communication disorders, as well as how this training should be delivered to medical students and physicians. Currently, it is uncertain whether physicians' ability to make accommodations to improve communication with these patients will improve as a result of receiving this training. Research should focus on checking for the presence of specific communication skills during these interactions, both with standardized patients and actual patients with communication disorders. Research should also help determine the optimal format in which to deliver this training, such as the most effective duration or number of hands-on interaction opportunities to provide.

Results of this study also helped inform the content of this training. Patients, caregivers, and physicians provided their insight into what they believed is important to teach medical students, including which accommodations might be the most useful to make with these patients. Further research can continue to inform the content of this training and how it should be delivered to physicians, as well as to other health care providers who interact with these patients. For example, the content of this training may look different based on the perspectives of patients and caregivers who were less satisfied with communication during medical interactions with physicians.

Recruiting patients with communication disorders for qualitative research.

Individuals with communication disorders are rarely included as participants in qualitative research studies, as it is often difficult for them to express their thoughts and perspectives without help from others when responding to interview questions (Mangset, Dahl, Førde, & Wyller, 2008; Tomkins, Siyambalapitiya, & Worrall, in press). However, based on the results of

this study, it is clear these individuals have important, valuable perspectives to share regarding their ideas and experiences. When conducting research to improve the lives of these individuals, especially when exploring their lived experiences and perspectives, it seems remiss to exclude them from this research. Researchers should actually be thinking about and developing ways to include these individuals in qualitative research, rather than excluding them from it.

Qualitative research studies involving individuals with communication disorders are emerging, with researchers using communication support strategies similar to those utilized in this study to interview participants (Tomkins et al., in press; Yorkston et al., 2007). The interviewing strategies used in this study to help patients with communication disorders co-construct their answers to questions provides an example of how researchers can strive to successfully include these individuals in future research. Only then can researchers feel the perspectives of these individuals are more accurately represented in their work.

Implications for Clinical Practice

In addition to informing future areas of research, results of this study have significant clinical implications for physicians and speech-language pathologists regarding patients with communication disorders. Results of this research highlight the need for providing medical students and practicing physicians with specific training to facilitate effective communication with these patients, and can inform the content of this training. These results also emphasize the importance of SLPs in providing this training, as well as identifying areas of intervention SLPs can target in their practice.

Clinical implications for physicians and other health care providers. Results of this study underscore the need for providing communication skills training related to patients with

communication disorders to medical students and practicing physicians. Patients and caregivers expressed the importance of physicians understanding how communication disorders can affect patients during medical interactions, as well as strategies that can be implemented to facilitate better communication with these patients. Physicians themselves also discussed the lack of communication skills training they received with these patients. They also commented on how valuable it would be for them to learn and have the opportunity for some hands-on practice with these communication-enhancing strategies. Providing communication skills training related to patients with communication disorders can help medical students and practicing physicians improve the accuracy and speed of communication that occurs during medical interactions. Improved communication can not only help physicians better understand the perspectives of their patients, but can also help them deliver care which is increasingly patient-specific and potentially more effective.

Results of this study can also inform the content included in this training. Patients, caregivers, and physicians provided ideas and recommendations for what physicians should know about communicating more effectively with patients with communication disorders. While all participants discussed specific strategies that physicians could implement to help improve communication, patients and caregivers also talked about the need for physicians to respect their patients who struggle to communicate and try to better understand their perspectives. Patients and caregivers commented that physicians should look at and speak to these patients directly as they would any other patients, as well as try to understand what these patients are going through and how they are feeling about struggling to communicate.

The results of this study also have implications for other members of the interdisciplinary health care team. While communication skills training is important for medical students and

practicing physicians, other health care disciplines and support staff have regular contact with patients with communication disorders and their caregivers. For example, nurses regularly interact with these patients, especially in an acute care or inpatient rehabilitation setting. Providing this type of communication skills training for these professionals can potentially help improve communication during these interactions as well.

Clinical implications for speech-language pathologists. The results of this study highlight the importance of the role SLPs can play in improving communication during medical interactions involving patients with communication disorders. Traditionally, SLPs focus their interventions on directly helping patients with communication disorders improve their ability to interact with others. However, as SLPs are beginning to focus their interventions on creating a more “communicatively accessible environment” (Simmons-Mackie, 2013, p. 99) for patients with communication disorders, they are beginning to look beyond the patients themselves to the environment in which they communicate. In medical interactions, this environment includes the caregivers and physicians with whom they are communicating.

Communication breakdowns can occur for a variety of reasons, and can involve any or all of the stakeholders in the interaction. For example, patients may not be able to adequately communicate symptoms to the physician who needs to make a diagnosis and develop potential treatment options. Physicians may not be able to communicate potential treatment options in a way the patient can understand. Caregivers may not be able to effectively translate to physicians what patients are trying to say, especially if they misunderstand the patients’ intended message. Fortunately, SLPs are trained to identify the source of communication breakdowns, as well as design and implement interventions to repair these breakdowns and prevent them from recurring in the future. In this way, SLPs are uniquely qualified to get involved in helping to improve

communication during medical interactions involving patients with communication disorders (Blackstone, Ruschke, Wilson-Stronks, & Lee, 2011; Burns et al., 2012; Wilson-Stronks & Blackstone, in press)

Interventions for patients with communication disorders. Speech-language pathologists traditionally focus their interventions on directly helping patients with communication disorders improve their ability to communicate effectively (Turner & Whitworth, 2006). However, these interventions typically focus on improving patients' communication across a variety of situations and contexts, and with a variety of communication partners. SLPs rarely focus their interventions on improving patients' communication during specific life activities, such as medical interactions. Perhaps focusing interventions on helping patients communicate with physicians and caregivers during medical interactions can potentially improve their ability to have their wants and needs heard, and to participate in shared decision-making about the care they receive. For example, helping patients improve their communication of important medical information can decrease their reliance on caregivers to provide this information during medical interactions. In addition, teaching patients self-advocacy skills such as using functional phrases or gestures to let physicians know how and when to accommodate their communication can help improve patients' comprehension of information during these interactions.

These patient-centered interventions need not be limited to actual face-to-face medical interactions. SLPs can help prepare patients for communicating more effectively during upcoming medical interactions or reviewing information physicians have provided to them from interactions that have already occurred. SLPs can help patients develop questions they want to ask physicians, practice asking these questions or communicating other important information before the actual medical interaction occurs. They can also help pre-program AAC devices with

important medical information for patients who use them. SLPs can also help patients better understand information physicians have communicated or provided to them from recent medical interactions. This information may be in regards to medications or potential courses of treatment on which patients need to decide.

Interventions for caregivers. Caregivers who participated in this study discussed that facilitating communication between patients and physicians can be difficult, and that caregivers are not always successful in fulfilling their role as facilitator. Similar results were found in a 2013 review of research exploring common problems faced by unpaid caregivers of individuals post-stroke with aphasia (McGurk & Kneebone, 2013). Results of this study suggested that two common problems these caregivers face are difficulties communicating with the individuals with aphasia they are caring for, and communicating with health care providers during medical interactions.

Recently, SLPs have begun focusing their interventions on training caregivers as communication partners for people with aphasia and other communication disorders. Research related to training caregivers of individuals with communication disorders as communication partners has been shown to be effective (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010; Turner & Whitworth, 2006). Programs, such as Supported Communication for Aphasia (Kagan, Black, & Duchan, 2001), focus on training communication partners of individuals with aphasia to successfully facilitate communication with them. However, like direct communication interventions for patients with communication disorders, these programs tend to focus on improving general communication across a variety of different contexts rather than during specific communication situations, such as medical interactions.

Perhaps SLPs can provide caregivers with training focused on helping them improve their ability to facilitate communication between patients and caregivers during medical interactions. The information communicated during medical interactions is often more complex and specific than a typical conversation, and the stakes can be much higher for making sure the information being communicated is accurate. SLPs can train caregivers to recognize when patients are struggling and need help with communication, and specifically what strategies can be used to help patients understand information or express themselves. SLPs can also train caregivers how to interact more effectively with physicians; helping caregivers demonstrate effective communication strategies with patients for physicians to learn, and to direct physicians' questions and information away from caregivers and back towards patients as appropriate. If caregivers can be more successful at facilitating communication during these medical interactions, it could help increase the patients' access to quality health care and improve the patients' overall health outcomes.

Interventions for physicians and other health care providers. Training physicians and other members of the interdisciplinary health care team how to improve interactions with patients with communication disorders can also be a focus of SLP intervention. Facilitating improved communication with these patients and integrating caregivers into triadic medical interactions is not easy, and requires a specific set of skills (Karnieli-Miller et al., 2012). As the results of this study have suggested, physicians are often expected, and often feel responsibility, to step up and direct communication during medical interactions, but may not have the training or skills to do so when patients struggle to communicate or when interactions involve additional people such as caregivers. SLPs are well suited to provide this training to physicians and other health care providers. Perhaps SLPs should focus their interventions on educating providers on

how communication disorders impact medical interactions, and strategies they can use to help improve communication during interactions with these patients.

As previously discussed, the PPC-CD training seminar at the UW Medical School has been educating fourth-year, and more recently second-year, medical students in using these communication strategies to facilitate improved interactions with patients across a variety of communication disorders since it was developed in 2010 (Burns et al., 2012). On-going research is being conducted with regards to this training, including the development of a protocol to standardize the training of simulated patients with communication disorders, and creation of an instrument to measure changes in medical students' communication behaviors as a result of PPC-CD training.

Results of the current study will be used to inform the content of the PPC-CD training seminar. Having a better understanding the perspectives and experiences of patients with communication disorders, their family caregivers, and physicians will help shape the focus of this training. For example, understanding that patients and caregivers work as a team to communicate with physicians during medical interactions, but that physicians should address patients directly and involve caregivers more like interpreters is information that can be directly disseminated to medical students enrolled in PPC-CD training. Additionally, advice that patients and caregivers offered for physicians to improve communication with these patients during medical interactions can (and will) be directly incorporated into the content of this training. In this way, training content is coming directly from those who have actually been involved in these medical interactions instead of solely from SLPs who may be making assumptions about the experiences of these individuals.

Conclusions

Research, including the results of this study, suggests that individuals with communication disorders can often become a vulnerable patient population in health care. Communication during medical interactions differs from that of a casual conversation; medical information can be complex and abstract, and the stakes are often high. The presence of communication disorders can further complicate medical interactions, creating communication breakdowns, and putting patients at risk for medical complications and poor health outcomes.

While their overall experiences have been positive, participants enrolled in this study expressed frustration at times regarding communication during medical interactions. Patients and caregivers felt that some physicians seemed unaware of the impact communication disorders had on these interactions, and that some physicians did not try to change their communication style to try and help struggling patients better understand and express themselves. Physicians, on the other hand, expressed an understanding for the importance of effective communication with these patients, and a desire to improve communication during these interactions. However, physicians discussed their lack of education and training regarding how to improve communication with these patients and their caregivers during medical interactions. Thus, there seems to be some fundamental differences in the perspectives patients and caregivers have compared perspectives of physicians regarding the potential source of communication breakdowns during medical interactions.

Results of this study also indicated that CAT may be a viable theory to explain and predict communication during medical interactions involving patients with communication disorders, their family caregivers and physicians. It is clear from the results of this study that medical students and practicing physicians should receive routine communication skills training

to learn how to facilitate effective communication with this patient population. There is potential for CAT to be used as a theoretical framework to develop a model-driven communication skills training program for physicians and other health care providers to help improve communication during these medical interactions. This training can help providers learn more about how communication disorders can impact medical interactions and how they can make appropriate accommodations to their communication to improve the effectiveness of these interactions.

Speech-language pathologists are uniquely qualified to develop and administer this training to providers. SLPs have the knowledge and clinical background to understand how communication can break down, as well as which accommodations can help to repair these breakdowns and prevent them from occurring in the future. In addition, SLPs can provide training patients with communication disorders and their caregivers specifically focused on helping them prepare to communicate with physicians during medical interactions. If communication can improve between patients with communication disorders and their physicians during these interactions, these patients can increase access to quality health care services, which can potentially improve their overall health.

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APPENDIX A: LIST OF STUDY PROCEDURES

Recruitment and Data Collection Procedures

1. Lead researcher recruited potential participants for study.
2. Participants were screened to determine if they meet inclusion criteria for study.
3. Participant interviews were conducted and audio and/or video recorded; demographic information was collected.
4. Participant interviews were transcribed; transcripts were uploaded into Dedoose.

Data Analysis Procedures

5. Initial two interviews were coded by lead researcher and secondary researchers; codes discussed and refined into code book.
6. Lead research coded two additional interviews; secondary researchers reviewed 10% of these transcripts for accuracy and reliability of coding.
7. Lead research coded remaining interviews.
8. Lead researcher sorted data by codes and developed summaries for each code across participants.
9. Lead researcher developed initial themes and subthemes from coded data.
10. Lead researcher met periodically with secondary researchers to discuss development of themes and subthemes, which were then finalized.

APPENDIX B: PATIENT RECRUITMENT FLYER

University of Washington Research Study

Do you have Aphasia, Dysarthria, or Apraxia of Speech?

Do you have problems talking with doctors during medical visits?

- We want to learn about communication during medical visits. We want to talk with people with communication difficulties. We also want to talk with their caregivers and doctors.
- We are looking for people who have aphasia, dysarthria and/or apraxia of speech. We are also looking for people who have had doctors' visits in the last 6 months. **YOU CAN HELP US LEARN ABOUT YOUR EXPERIENCES!!**
- We will interview you and your caregiver two (2) times at the UW Speech and Hearing Clinic or at your home. Each interview will take 60-90 minutes. We will pay you \$25.00 for each interview.
- **This study is voluntary. You do not have to volunteer.**

If you are interested in learning more about this study, please email or call

Mike Burns

mburns@uw.edu or (206)543-0597

Please remember we cannot guarantee the confidentiality of any information sent by email

Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597	Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597	Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597	Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597
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APPENDIX C: RECRUITMENT SCRIPT FOR PATIENTS WITH COMMUNICATION
DISORDERS FOR THE APHASIA REGISTRY AND REPOSITORY (EMAIL)

Hello. My name is Michael Burns. I am a doctoral student at the University of Washington.

I obtained your name and email address from the Aphasia Registry and Repository.

I am emailing you to see if you would like to be part of a research study.

This study is voluntary. You do not have to participate.

We want to learn about communication between patients with communication difficulties, their caregivers, and doctors during medical visits.

The purpose of the study

Talking with doctors during medical visits can be hard for patients who have trouble communicating. Making this communication better will hopefully improve the medical care that patients with communication difficulties receive. This research will help us train doctors to improve their communication with patients like you during medical visits.

What the study involves

We are interviewing people who have trouble communicating. We are also interviewing their caregivers and doctors. We want to learn about their communication during medical visits.

If you qualify, we will interview you and your caregiver two times, once together and once by yourselves. Each interview will last about 60-90 minutes and will be scheduled 1-2 weeks apart.

You can stop the interview at any time and take breaks as needed.

You will be paid \$25.00 for each interview you complete.

Who is eligible for the study?

To be in this study, you need to have aphasia, dysarthria, or apraxia of speech.

You also need to be 18 or older, and have had a doctor visit in the last 6 months.

Your caregiver needs to be a family member. He or she also needs to be 18 years or older, and have provided care in the last 6 months.

How can I get more information about this study?

If you are interested in being part of this study or want more information, please contact me.

My email address is mburns@uw.edu.

I can answer your questions and let you know if you qualify for the study.

Thank you for your time.

Michael Burns, Ph.C., CCC-SLP
University of Washington
Department of Rehabilitation Medicine

APPENDIX D: PHYSICIAN RECRUITMENT FLYER

Is it hard talking with patients with communication difficulties?

- We want to learn about communication during medical visits. We are looking to interview people with communication difficulties, their caregivers, and physicians.
- We are looking for physicians in the UW Medical System who have spoken with patients with communication difficulties in the last 6 months. WE WOULD LIKE TO LEARN ABOUT YOUR EXPERIENCES!!!
- We will interview you in the Department of Rehabilitation Medicine at the UW Medical Center. Interviews will last 60-90 minutes.
- This study is voluntary.

If you are interested in learning more about this study, please email or call

Mike Burns, Ph.C., CCC-SLP
[mburns@uw.edu](mailto:m burns@uw.edu) or (206)543-0597

Please remember we cannot guarantee the confidentiality of any information sent by email

Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597	Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597	Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597	Communication during medical appointments Mike Burns mburns@uw.edu (206)543-0597
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APPENDIX E: PATIENT CONSENT FORM

UNIVERSITY OF WASHINGTON

CONSENT FORM

Communication in Medical Interactions: Perspectives of Individuals with Communication Disorders, Their Caregivers, and Physicians**(Patient)**

Investigators	Title	Department	Address	Phone
Michael Burns, PhC	PhD Student, Primary Investigator	Rehabilitation Medicine	Box 356490	206-543-0597
Carolyn Baylor, PhD	Acting Assistant Professor	Rehabilitation Medicine	Box 356490	206-221-3563
Kathryn Yorkston, PhD	Professor	Rehabilitation Medicine	Box 356490	206-543-3345
Brian J. Dudgeon, PhD	Associate Professor	Rehabilitation Medicine	Box 356490	206-598-5412
Diane Kendall, PhD	Associate Professor	Speech and Hearing Sciences	Box 354875	206-685-2140
Helene Starks, PhD	Associate Professor	Bioethics and Humanities	Box 357120	206-543-5145
Tom McNally, MD	Chronic Care Clerkship Director	Rehabilitation Medicine	Box 356490	206-616-6345

RESEARCHER'S STATEMENT

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be in the study. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." We will give you a copy of this form for your records.

PURPOSE OF THE STUDY

Good communication between doctors and patients is important to improve patient health and satisfaction. It also helps decrease medical costs and malpractice claims.

The purpose of this study is to learn about communication between people with communication difficulties, their caregivers and physicians during medical visits. The purpose of this interview is to learn about your experiences with communication during these medical visits.

STUDY PROCEDURES

This study is voluntary. Whether or not you decide to be in this study, the health care services you receive will not be affected.

If you decide to be in this study, you will be interviewed 2 times. Interviews will be scheduled 1-2 weeks apart. During the first interview, you and _____ will be asked about your joint experiences talking with doctors. During the second interview, you will be asked about your individual experiences with communication during these medical visits. Each interview will be led by a licensed speech-language pathologist.

During these interviews, you will be asked questions about your communication during medical visits. Examples of potential interview questions include:

“What do you think doctors need to know to successfully communicate with patients with communication difficulties?”

“What strategies have been the most helpful in improving communication with doctors during medical visits?”

You do not have to answer every question. There are no right or wrong answers to any of the questions. The interview is expected to last no more 2 hours. You can take breaks whenever you need them.

We would like to video-record these interviews to have accurate information. The recordings will be kept in a secure place until all of the interviews are finished. They will be destroyed by August 31, 2013, unless you give us written permission to use them for research or public presentations.

We will also be interviewing doctors. We want to learn about their experiences during these medical visits as well. One of the doctors we interview may have provided care for you. You

may have been present during the medical visits we discuss. We may discuss communication that happened during these visits.

RISKS, STRESS, OR DISCOMFORT

Some people may feel self-conscious when being interviewed. There are no right or wrong answers to the questions. You do not have to answer every question. Some people may feel self-conscious being recorded. Breach of confidentiality is a risk to being in the study if it happens that your information is accidentally given to or taken by persons who should not see it.

ALTERNATIVES TO TAKING PART IN THIS STUDY

The alternative to participating in this study is not participating. You can choose not to take part in this study. You can also choose to answer some questions and not others. You can stop the interview at any time. You can take breaks as needed.

BENEFITS OF THE STUDY

You may not directly benefit from taking part in this study. We hope the results of this study will help improve training doctors receive for talking with patients who have communication difficulties.

OTHER INFORMATION

You do not have to be part of this study. You can choose to say no. You can stop at any time.

Researchers helping with this study will have access to information you provide as part of the study. We will keep this information confidential. We will assign a unique study code to your responses. We will keep personal identifiers in a secure place, separate from your responses until no later than one year after your interviews are completed. At that time we will destroy the link. If the results of this study are published or presented, we will not use your name. We will not use audio or video recordings in public presentations unless you give us written permission to do so.

We may ask for your permission to use brief segments of video recordings outside the research study. In that case, we will give you a chance to review the segments before giving us your written permission to use them.

If you participate in this interview, you will receive a check for \$25 at the end of the interview.

Government or university staffs sometimes review studies to make sure they are being done safely and legally. If a review of this study takes place, any audio or video recordings and transcripts of the discussion may be examined.

The reviewers will protect your privacy. These recordings and transcripts will not be used to put you at legal risk of harm.

We may want to re-contact you in order to clarify information you have discussed. Please indicate below whether or not you give your permission for us to re-contact you. Giving your permission to re-contact you does not obligate you in any way.

If you have questions about the study, you may contact Michael Burns at 1959 NE Pacific Street, Box 356490, Seattle, WA 98195-7920 or call 206-543-0597 or email mburns@uw.edu. Although we make every effort to protect your privacy, please note that the confidentiality of email cannot be guaranteed.

 Printed name of researcher

Signature of researcher

Date

PARTICIPANT'S STATEMENT

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I give the researchers permission to audio record the focus group session as described above in this consent form. I will receive a copy of this consent form.

_____ I give my permission for the researchers to re-contact me to clarify information.

_____ I do NOT give my permission for the researchers to re-contact me to clarify information

 Printed name of participant

Signature of participant

Date

PERMISSION FOR USE OF VIDEO RECORDINGS

If you have chosen to participate in this study, we may video record you during an interview. We would like to keep the video recording to use for our research forever.

It is possible for someone who knows you to recognize your face, body, or clothing.

We request your permission for the research team to use these video recordings in the following way(s):

- Academic public presentations
- Educational settings
- Web-based setting
- Scientific or educational journals
- Keep the video recordings for research purposes indefinitely.

As part of this study, you will be given an opportunity to review these video recording(s) prior to their use. Even if you give us permission now, we will not use them if you later decide you do not want us to.

Printed name of researcher

Signature of researcher

Date

PARTICIPANT'S STATEMENT

I give my permission to the researchers to use video recordings obtained as part of this study as I have indicated above in this consent form. I understand I will have the opportunity to review these video recordings as part of this study and can later decide I do not want them to be used by the research team.

I understand that my name will not be published in connection with any presentation or publication developed from the results of this study. I will not receive any compensation for the use of the video recordings.

I will receive a copy of this consent form.

Printed name of participant

Signature of participant

Date

Copies to: Investigator's file
 Participant

APPENDIX F: CAREGIVER CONSENT FORM

UNIVERSITY OF WASHINGTON

CONSENT FORM

Communication in Medical Interactions: Perspectives of Individuals with Communication Disorders, Their Caregivers, and Physicians**(Caregiver)**

Investigators	Title	Department	Address	Phone
Michael Burns, PhC	PhD Student, Primary Investigator	Rehabilitation Medicine	Box 356490	206-543-0597
Carolyn Baylor, PhD	Acting Assistant Professor	Rehabilitation Medicine	Box 356490	206-221-3563
Kathryn Yorkston, PhD	Professor	Rehabilitation Medicine	Box 356490	206-543-3345
Brian J. Dudgeon, PhD	Associate Professor	Rehabilitation Medicine	Box 356490	206-598-5412
Diane Kendall, PhD	Associate Professor	Speech and Hearing Sciences	Box 354875	206-685-2140
Helene Starks, PhD	Associate Professor	Bioethics and Humanities	Box 357120	206-543-5145
Tom McNally, MD	Chronic Care Clerkship Director	Rehabilitation Medicine	Box 356490	206-616-6345

RESEARCHER'S STATEMENT

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be in the study. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." We will give you a copy of this form for your records.

PURPOSE OF THE STUDY

Good communication between doctors and patients is important for improved patient health and satisfaction. It also helps decrease medical costs and malpractice claims. The purpose of this study is to learn about communication between people with communication difficulties, their caregivers and physicians during medical visits. The purpose of this interview is to learn about your experiences with communication during these medical visits.

STUDY PROCEDURES

This study is voluntary. If you decide to be in this study, you will be interviewed 2 times. Interviews will be scheduled 1-2 weeks apart. During the first interview, you and _____ will be asked about your joint experiences talking with doctors. During the second interview, you will be asked about your individual experiences with communication during these medical visits. Each interview will be led by a licensed speech-language pathologist.

You will be asked questions about your involvement during these medical visits. Examples of interview questions include, “What do you think doctors need to know to successfully communicate with patients with communication difficulties?” and “What strategies have been the most helpful in improving communication with doctors during medical visits?” You do not have to answer every question. There are no right or wrong answers to any of the questions. The interview will last no more 2 hours. You can take breaks whenever you need them.

We would like to record these interviews to have accurate information. We will keep recordings in a secure place until all of the interviews are finished. They will be destroyed by August 31, 2013, unless you give us written permission to use them for research or public presentations.

We will also be interviewing doctors about their experiences during these medical visits. One of the doctors we interview may have provided care for _____. You may have been present during the medical visits we discuss. We may discuss communication that happened during these visits.

RISKS, STRESS, OR DISCOMFORT

Some people may feel self-conscious when being interviewed. There are no right or wrong answers to the questions. You do not have to answer every question. Some people may feel self-conscious being recorded. Breach of confidentiality is a risk to being in the study if it happens that your information is accidentally given to or taken by persons who should not see it.

ALTERNATIVES TO TAKING PART IN THIS STUDY

The alternative to participating in this study is not participating. You can choose not to take part in this study. You can also choose to answer some questions and not others. You can stop the interview at any time, and take breaks as needed.

BENEFITS OF THE STUDY

You may not directly benefit from taking part in this study. We hope the results of this study will help improve training doctors receive for talking with patients who have communication difficulties.

OTHER INFORMATION

Taking part in this study is voluntary. You can stop at any time.

Researchers helping with this study will have access to information you provide as part of the study. We will keep this information confidential. We will assign a unique study code to your responses. We will keep personal identifiers in a secure place, separate from your responses until no later than one year after your interviews are completed. At that time we will destroy the link. If the results of this study are published or presented, we will not use your name. We will not use audio or video recordings in public presentations unless you give us written permission to do so.

We may ask for your permission to use brief segments of video recordings outside the research study. In that case, we will give you a chance to review the segments before giving us your written permission to use them.

You will receive a check for \$25 at the end of each interview you complete.

Government or university staffs sometimes review studies to make sure they are being done safely and legally. If a review of this study takes place, any audio or video recordings and transcripts of the discussion may be examined. The reviewers will protect your privacy. These recordings and transcripts will not be used to put you at legal risk of harm.

We may want to re-contact you in order to clarify information you have discussed. Please indicate below whether or not you give your permission for us to re-contact you. Giving your permission to re-contact you does not obligate you in any way.

If you have questions about the study, you may contact Michael Burns at 1959 NE Pacific Street, Box 356490, Seattle, WA 98195-7920 or call 206-543-0597 or email mburns@uw.edu. Although we make every effort to protect your privacy, please note that the confidentiality of email cannot be guaranteed.

 Printed name of researcher

Signature of researcher

Date

PARTICIPANT'S STATEMENT

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I give the researchers permission to audio or video record the interview(s) described above in this consent form. I will receive a copy of this consent form.

_____ I give my permission for the researchers to re-contact me to clarify information.

_____ I do NOT give my permission for the researchers to re-contact me to clarify information

 Printed name of participant

Signature of participant

Date

PERMISSION FOR USE OF VIDEO RECORDINGS

If you have chosen to participate in this study, we may video record you during an interview. We would like to keep the video recording to use for our research forever.

It is possible for someone who knows you to recognize your face, body, or clothing.

We request your permission for the research team to use these video recordings in the following way(s):

- Academic public presentations
- Educational settings
- Web-based setting
- Scientific or educational journals
- Keep the video recordings for research purposes indefinitely.

As part of this study, you will be given an opportunity to review these video recording(s) prior to their use. Even if you give us permission now, we will not use them if you later decide you do not want us to.

Printed name of researcher	Signature of researcher	Date
----------------------------	-------------------------	------

PARTICIPANT'S STATEMENT

I give my permission to the researchers to use video recordings obtained as part of this study as I have indicated above in this consent form. I understand I will have the opportunity to review these video recordings as part of this study and can later decide I do not want them to be used by the research team.

I understand that my name will not be published in connection with any presentation or publication developed from the results of this study. I will not receive any compensation for the use of the video recordings.

I will receive a copy of this consent form.

Printed name of participant	Signature of participant	Date
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Copies to: Investigator's file
 Participant

APPENDIX G: PHYSICIAN CONSENT FORM

UNIVERSITY OF WASHINGTON

CONSENT FORM

Communication in Medical Interactions: Perspectives of Individuals with Communication Disorders, Their Caregivers, and Physicians**(Physician)**

Investigators	Title	Department	Address	Phone
Michael Burns, PhC	PhD Student, Primary Investigator	Rehabilitation Medicine	Box 356490	206-543-0597
Carolyn Baylor, PhD	Acting Assistant Professor	Rehabilitation Medicine	Box 356490	206-221-3563
Kathryn Yorkston, PhD	Professor	Rehabilitation Medicine	Box 356490	206-543-3345
Brian J. Dudgeon, PhD	Associate Professor	Rehabilitation Medicine	Box 356490	206-598-5412
Diane Kendall, PhD	Associate Professor	Speech and Hearing Sciences	Box 354875	206-685-2140
Helene Starks, PhD	Associate Professor	Bioethics and Humanities	Box 357120	206-543-5145
Tom McNally, MD	Chronic Care Clerkship Director	Rehabilitation Medicine	Box 356490	206-616-6345

RESEARCHER'S STATEMENT

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be in the study. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." We will give you a copy of this form for your records.

PURPOSE OF THE STUDY

Good communication between doctors and patients is important for improved patient health and satisfaction. It also helps decrease medical costs and malpractice claims. The purpose of this study is to learn about communication between people with communication difficulties, their caregivers and physicians during medical visits. The purpose of this interview is to learn about your experiences with communication during these medical visits.

STUDY PROCEDURES

This study is voluntary. If you decide to be in this study, you will be interviewed by one of the study investigators. During the interview, you will be asked about your experiences communicating with patients with communication difficulties and their caregivers during medical visits. Each interview will be led by a licensed speech-language pathologist.

Examples of potential interview questions include, “Describe the challenges you have experienced when communicating with patients who have communication difficulties.” and “What should be included in training focused on helping health care providers communicate with patients with communication difficulties?” You do not have to answer every question. There are no right or wrong answers to any of the questions. The interview is expected to last no more than 90 minutes. You can take breaks during the interview whenever you need them.

We would like to audio-record these interviews to have accurate information. The recordings will be kept in a secure location until we have completed all of the interviews and gathered all of the information. These recordings will be destroyed no later than one year after they are collected, or by August 31, 2013.

We will also be interviewing patients with communication difficulties and their caregivers. You may have provided care for one of the patients we interview. Their caregiver may have also been part of the medical visit(s) in which you provided this care. We may discuss communication during these visits.

RISKS, STRESS, OR DISCOMFORT

Some people may feel self-conscious when taking part in an interview. There are no right or wrong answers to the questions. You do not have to answer every question. Some people may feel self-conscious being audio-recorded. Breach of confidentiality is a risk to being in the study if it happens that your information is accidentally given to or taken by persons who should not see it.

ALTERNATIVES TO TAKING PART IN THIS STUDY

The alternative to participating in this study is not participating. You can choose not to take part in this study. You can also choose to provide answers only for certain questions and not others. You can also stop the interview at any time, or take breaks as needed.

BENEFITS OF THE STUDY

You may not directly benefit from taking part in this study. We hope the results of this study will help improve training doctors receive for talking with patients who have communication difficulties.

OTHER INFORMATION

Taking part in this study is voluntary. You can stop at any time.

Researchers helping with this study will have access to information you provide as part of the study. We will keep this information confidential. We will assign a unique study code to your responses. We will keep personal identifiers in a secured location, separate from your responses until no later than one year after your interviews are completed. At that time we will destroy the link. If the results of this study are published or presented, we will not use your name or images. We will not use audio recordings in public presentations.

Government or university staffs sometimes review studies to make sure they are being done safely and legally. If a review of this study takes place, any audio or video recordings and transcripts of the discussion may be examined. The reviewers will protect your privacy. These recordings and transcripts will not be used to put you at legal risk of harm.

We may want to re-contact you in order to clarify information you have discussed. Please indicate below whether or not you give your permission for us to re-contact you. Giving your permission to re-contact you does not obligate you in any way.

If you have questions about the study, you may contact Michael Burns at 1959 NE Pacific Street, Box 356490, Seattle, WA 98195-7920 or call 206-543-0597 or email mburns@uw.edu. Although we make every effort to protect your privacy, please note that the confidentiality of email cannot be guaranteed.

Printed name of researcher

Signature of researcher

Date

PARTICIPANT'S STATEMENT

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I give the researchers permission to audio or video record the interview(s) described above in this consent form. I will receive a copy of this consent form.

_____ I give my permission for the researchers to re-contact me to clarify information.

_____ I do NOT give my permission for the researchers to re-contact me to clarify information

Printed name of participant

Signature of participant

Date

Copies to: Investigator's file
 Participant

APPENDIX H: PATIENT AND CAREGIVER JOINT INTERVIEW GUIDE

Communication in Medical Interactions: Perspectives of Individuals with Communication Disorders, Their Caregivers, and Physicians

Patient and Caregiver Interview Guide – Initial (joint)

Thank you for participating in this study.

We want to learn about your experiences talking with _____’s doctors during medical visits.

Today we will ask you questions about your joint experiences.

With your permission, we will video record this interview. This helps make sure we accurately record what you say. Some people we interview may have trouble communicating with words. They may use gestures or other ways of communicating that do not involve talking. Video recording will help us record that communication as well.

There is no “right” or “wrong” answer to any of these questions. Your responses will be kept confidential. As a reminder, you do not have to participate in this study. You can refuse to answer any of these questions. You can also stop the interview or take a break at any time.

Do you have any questions before we begin?

1. To begin, what is it like talking with your doctor(s)?
 - a. Tell me about a medical visit _____ (individual with comm disorder) has had with a doctor in which you were both present where communication went well.
 - b. Tell me about a medical visit _____ (individual with comm disorder) has had with a doctor in which you were both present where communication did not go well.
2. Do you prepare for your medical visits before you go?
 - a. (If yes)... How?
 - b. (If no)... Why not?
 - c. Do you use the internet to find medical information?
 - i. (if yes)...Tell me about how you use that information.
 - ii. (if no)...Does someone in your family help you use the internet? Do they use it for you to get medical information? Tell me about that.
3. If you have trouble communicating with doctors, what do you do (if anything)?

4. What have you tried to help communication that has worked well for both of you when talking with doctors?
 - a. What have you tried that did not work well?
5. What information do you think doctors should know when talking with you?
6. What do you think doctors should be trained to do when talking with you?

Wrap-up

1. Those are all the questions I have for you. Is there anything else either of you would like to add?
2. Do either of you have any questions for me?

Thank you for your participating in this interview. You have given us valuable information.

We would like to schedule a second interview within 1-2 weeks. At that time, we will interview you individually. We want to learn about each of your perspectives about talking to doctors during medical appointments.

APPENDIX I: PATIENT INDIVIDUAL INTERVIEW GUIDE

Exploring Patient-Provider Communication when Patients have Communication Disorders

Patient Interview Guide – 2nd interview (individual)

Thank you for agreeing to participate in this study today.

The purpose of this study is to learn about the experiences of people with communication difficulties, their caregivers, and physicians related to communication during medical appointments.

We have already talked with you and _____ about your joint perspectives on communication with your doctors.

This interview will give you a chance to answer questions in your own words.

With your permission, we will video record this interview to make sure we correctly record what you say. Some people being interviewed have difficulty communicating with words, so video recording is being used instead of audio recording. This way we can record verbal and nonverbal communication that may be used to answer questions.

There is no “right” or “wrong” answer to any of these questions. Your comments will be kept confidential. You can refuse to answer any of these questions. You can stop the interview or take a break at any time.

Is there anything talked about before that you would not like to talk about during this interview?

We have few more questions to ask you about talking with your doctors during medical visits.

1. Tell me about your experiences talking with doctors.
2. As a patient, how are you involved in your medical visits?
3. How do you think you should be involved?
4. How do you think _____ (caregiver) should be involved?
5. How do you think your doctors should be involved?
6. Do you feel like you are involved in making decisions about your medical care?
7. What should doctors know to communicate better with you?
 - a. What should they do to communicate better?
8. What should caregivers know so they can be more helpful during medical visits?

- a. What should they do to help improve communication?
9. What should patients with communication difficulties know to communicate better with doctors?
 - a. What should they do to improve communication?

Wrap up

10. Those are all the questions I have for you. Is there anything else you'd like to say?
11. Do you have any questions for me?

Thank you for letting us interview you. We plan on using this information to help train doctors to improve communication with their patients with communication difficulties and their caregivers.

Can we contact you with additional questions to clarify your responses if needed?

If you have any questions about the study or what we have discussed, please contact me.

APPENDIX J: CAREGIVER INDIVIDUAL INTERVIEW GUIDE

Exploring Patient-Provider Communication when Patients have Communication Disorders

Caregiver Interview Guide – 2nd interview (individual)

Thank you for agreeing to participate in this study today.

The purpose of this study is to learn about the experiences of people with communication difficulties, their caregivers, and physicians related to communication during medical visits.

You have already been interviewed with _____ to learn about your joint communication experiences with doctors. This interview will give you a chance to talk about your perspective and answer questions in your own words.

With your permission, we will audio record this interview to be sure we accurately document what you say. Written transcripts will be created from these audio recordings.

There are no “right” or “wrong” answer to any of these questions. Your comments will be kept confidential. You can refuse to answer any of these questions, and can stop the interview or take a break at any time.

Are there any topics or ideas we talked about during the last interview that you would not like to talk about this time?

We would like to ask you a few more questions about your experiences talking with _____ and his/her doctors during medical visits.

1. Tell me about your experiences talking with doctors during _____’s (individual with communication disorder) medical visits.
2. As a caregiver, how are you involved in these medical visits?
3. How do you think you should be involved?
4. How do you think _____ should be involved?
5. How do you think the doctor should be involved?
6. Are you involved in decisions about _____’s care during medical visits? Tell me about that.
7. What do you think doctors need to know to communicate better with patients like _____?
 - a. What do you think they need to do to help this communication?

8. What do you think patients need to know to communicate better during these medical visits?
 - a. What do you think they need to do to help this communication?
9. What do you think caregivers need to know to communicate better during these medical visits?
 - a. What do you think they need to do to help this communication?

Wrap-up

10. Those are all the questions I have for you. Is there anything else you'd like to add?
11. Do you have any questions for me?

We will transcribe the responses you gave us today for analysis. We plan on using this information to help train doctors to improve communication with their patients with communication difficulties and their caregivers.

Can we contact you with additional questions to clarify your responses if needed?

If you have any questions about the study or what we have discussed, please contact me.

APPENDIX K: PHYSICIAN INTERVIEW GUIDE

Exploring Patient-Provider Communication when Patients have Communication Disorders

Physician Interview Guide

Thank you for agreeing to participate in this study today.

We want to learn about the communication experiences of people with communication difficulties, their caregivers, and doctors during medical visits. Today, we would like to learn about your experiences communicating with these patients during medical visits.

With your permission, we will audio record this interview to be sure we accurately document what you say. Written transcripts will be created from these audio recordings.

There are no “right” or “wrong” answer to any of these questions. Your comments will be kept confidential. As a reminder, this study is voluntary. You can refuse to answer any of these questions, and can stop the interview or take a break at any time.

1. Tell me about your experiences communicating with patients with communication difficulties.
 - a. Tell me about a medical visit you have had with a patient with a communication disorder where communication went well.
 - b. Tell me about a medical visit you have had with a patient with a communication disorder where communication went poorly.
2. Describe the challenges you have had communicating with patients who have communication disorders.
3. If communication problems occur during medical visits, what do you do (if anything)?
4. Who else is involved in decision-making regarding patients with communication difficulties?
5. Are there any changes in your clinical practice procedures that would help you talk with patients with communication difficulties?
6. What should be included in training focused on helping health care providers communicate with patients?
7. Have your patients with communication difficulties come to medical visits with information from the internet to ask questions?
 - a. Does this happen more/less frequently than the average patient you meet with?
 - b. Is this information generally helpful as part of the medical visit?
8. Is there anything else you would like to discuss on this topic?

Wrap up

9. Those are all the questions I have for you. Is there anything else you'd like to add?
10. Do you have any questions for me?

Thank you for participating in this interview. We will transcribe your responses for analysis. We plan on using this information to help train doctors to improve communication with their patients with communication difficulties and their caregivers.

Can we contact you with additional questions to clarify your responses if needed?

If you have any questions about the study or what we have discussed, please contact me.

APPENDIX L: PATIENT DEMOGRAPHIC INFORMATION FORM

Demographic Information Form (Patient)

1. Age: _____

2. Gender:

Male

Female

3. Primary language: _____

4. Racial / ethnic group:

American Indian / Alaskan Native

Asian

Native Hawaiian or other Pacific Islander

Black or African American

White (Caucasian)

Hispanic or Latino

More than one

5. Please mark the highest educational level completed:

Elementary or junior high school

Some high school

High school graduate or GED

Vocational or technical school

Some college

College graduate

Post-graduate (Master's; Ph.D.)

6. What is your current work status? Check ALL that apply

Working full time for pay outside the home

Working part time for pay outside the home

Working for pay in a home-based business

Working as a volunteer

Working at home as a homemaker, stay-at-home parent, or care provider for other family members

Attending school or job training

- Retired, and retirement was NOT related to current medical diagnosis
 Not working or retired early because of medical condition
 Not working for other reasons. Please describe: _____
7. What is your occupation (or what was your occupation at the time you stopped working)?

8. With whom do you currently live?
- I live alone
 Family (spouse or domestic partner, children, parents, other relatives)
 Friends / Roommate
 Assisted Living or Adult Family Home
 Other, Please describe: _____
9. In which state in the US do you live? _____
10. What is your communication disorder?
11. How long ago did you start having symptoms of your communication disorder?
12. Are your communication symptoms related to any other medical condition (such as stroke, Parkinson's disease, etc.)? If so, when were you diagnosed with this medical condition?
13. Have you had any treatment for your communication symptoms? If so, what was the treatment and when did the most recent treatment end? What impact did the treatment have on your ability to communicate?
14. Do you regularly use any other method of communication in addition to or instead of speech to help you communicate?
15. Did you have any problems with your speech, language or memory prior to this medical condition?
- No
 Yes, Please describe: _____
17. Do you have any other medical conditions that, in your opinions, affect your participation in day to day activities?
- No
 Yes, Please describe: _____
18. Which statement best describes your hearing:
- I do not have any problems with my hearing

- I do have problems with my hearing but I do not wear hearing aids or other assistive devices
- I do have problems with my hearing and I do wear hearing aids or other assistive Device

19. Which statement best describes your speech / language?

- Normal
- Sounds different but people understand me
- Sometimes have to repeat words to be understood
- Use gestures, writing or drawing to help people understand my speech
- Not understandable; I do not use speech for communication

20. Are there any activities (including those for your job or outside of your job) for which speech is particularly important to you (e.g. community groups, public speaking, singing, etc)? If so, please list 2 or 3 of these:

APPENDIX M: CAREGIVER DEMOGRAPHIC INFORMATION FORM

Demographic Information Form (Caregiver)

1. Age: _____

2. Gender:

Male

Female

3. Primary language: _____

4. Racial / ethnic group:

American Indian / Alaskan Native

Asian

Native Hawaiian or other Pacific Islander

Black or African American

White (Caucasian)

Hispanic or Latino

More than one

5. Please mark the highest educational level completed:

Elementary or junior high school

Some high school

High school graduate or GED

Vocational or technical school

Some college

College graduate

Post-graduate (Master's; Ph.D.)

6. What is your current occupation? (or what was your occupation at the time you stopped working)? _____

7. Which of the following *best* describes *how often* do you provide routine care (i.e. dressing, bathing, cooking) for your family member with a communication disorder?

Rarely (I help out every once in a while when needed)

Often (I provide care about 50% of the time)

Regularly (I help provide care most of the time)

Constantly (I help with nearly every aspect of his/her care)

8. Which of the following *best* describes *how often* do you accompany your family member with a communication disorder to his/her medical visits?

Rarely (maybe every once in a while)

Often (I go with him/her 50% of the time)

Regularly (I go to most appointments)

Constantly (I go to all of his/her medical appointments)

9. Which of the following *best* describes *how often* do you communicate for your family member with a communication disorder during his/her medical visits?

Rarely (he/she can communicate most of the time without my help)

Often (I will speak for him/her about 50% of the time)

Regularly (I speak for him/her at least 75% of the time)

Constantly (I speak for him/her nearly all the time)

APPENDIX N: PHYSICIAN DEMOGRAPHIC INFORMATION FORM

Demographic Information Form (Physician)

1. Number of years as a physician: _____
2. Medical specialty (i.e. general practice, neurology, etc.): _____
3. Primary language: _____
4. Gender:
 Male
 Female
5. Racial / ethnic group:
 American Indian / Alaskan Native
 Asian
 Native Hawaiian or other Pacific Islander
 Black or African American
 White (Caucasian)
 Hispanic or Latino
 More than one
6. Which of the following best characterizes the number of patients with communication disorders you currently encounter in your practice?
 A few (fewer than 5 patients each year)
 Some (about 1-2 patients per month)
 Quite a few (about 1-2 patients per week)
 Many (about 4+ patients per week)
7. In your medical education, did you receive training specific to improving patient-provider communication (PPC)?
 Yes
 No
8. If so, did this training discuss how to communicate effectively with patients with communication disorders?
 Yes
 No

APPENDIX O: CODE BOOK

<u>Name</u>	<u>Description</u>
Caregiver	Information related to the caregiver as a stakeholder in communication during medical interactions.
Attribute	Traits or qualities of caregivers that are perceived to impact communication during a medical interaction.
Role	Perceived responsibilities of caregivers related to communication during medical interactions.
Strategy	Methods or skills employed by caregivers to help improve/facilitate communication during medical interactions.
Communication	Information generally related to communication during medical interactions.
Barrier	Sources of difficulty that inhibit/prevent good PPC from occurring during a medical interaction.
Facilitator	Circumstances or factors that facilitate/promote communication during a medical interaction.
Advice	Advice for stakeholders involved in medical interactions to help facilitate/promote communication.
Information	Printed or electronic materials used to communicate information during medical visits.
Change	Circumstances or factors that cause the effectiveness of communication during medical interactions to vary over time.
Outcome	Consequences or effects of poor PPC.
Specific Situation	Unique communication situations discussed by participants during medical interactions.
Good quote	Memorable, illustrative participant quotes.
Patient	Information related to the patient as a stakeholder in communication during medical interactions.
Attribute	Traits or qualities of patients that are perceived to impact communication during medical interactions.
Role	Perceived responsibilities of patients in communication during medical interactions.
Strategy	Methods or skills employed by patients to help improve/facilitate communication during medical interactions.
Physician	Information related to the physician as a stakeholder in communication during medical interactions.

<u>Name</u>	<u>Description</u>
Attribute	Traits or qualities of physicians that are perceived to impact communication during medical interactions.
Role	Perceived responsibilities of physicians involved in communication during medical interactions.
Strategy	Methods or skills employed by physicians to help improve/facilitate communication during medical interactions.
Story	Narrative provided by patient, caregiver, or physician related to their experiences with communication during medical interactions.
Team	Information related to patient and caregiver communicating together with physicians during medical interactions.

APPENDIX P: DESCRIPTION OF PATIENTS' COMMUNICATION DISORDERS

Description of Patients' Communication Disorders			
	Medical Diagnosis	Communication Disorder Diagnosis	Description of Communication Disorder
P1	Stroke	Mild-Moderate Aphasia; Moderate Apraxia of Speech	Intermittent word finding difficulty; speech limited mostly to short phrases or simple sentences; auditory comprehension breaks down at sentence level.
P2	Stroke	Mild-Moderate Aphasia	Prolonged periods of word finding difficulty amidst otherwise fluent speech; mild deficits in attention and working memory skills.
P3	Stroke	Moderate Aphasia; Severe Apraxia of Speech	Prolonged period of word finding difficulty; speech limited to single words or stereotypic phrases; auditory comprehension breaks down at sentence level.
P4	Unknown	Mild-Moderate Primary Progressive Aphasia (PPA); Mild-Moderate Apraxia of Speech	Intermittent word finding difficulty; occasional sound distortions and substitutions at conversation level; moderate deficits in short-term memory.
P5	Stroke	Moderate-Severe Aphasia; Moderate Apraxia of Speech	Significant word finding difficulty; auditory comprehension breaks down at sentence/conversation level.
P6	Stroke	Mild-Moderate Aphasia; Moderate Apraxia of Speech	Intermittent word retrieval difficulty; slow, effortful-appearing speech limited mostly to single words or short phrases; auditory comprehension breaks down at sentence/conversation level.

APPENDIX Q: ROLE OF PATIENTS

Role of Patients

<u>Role Description</u>	<u>Participant Quotes</u>
Reporter of symptoms and medical issue.	<i>(Described by all patients and caregivers during interviews)</i>
Self-advocate for independence and autonomy in communication and decision-making.	<p data-bbox="574 552 1256 585"><i>"I want to try...all the time. I want my own life." (P1)</i></p> <p data-bbox="574 600 1062 634"><i>"It's very hard...I need to speak." (P1)</i></p> <p data-bbox="574 648 1409 716"><i>"It's important for me to be...part of the family. I don't want to be useless." (P2)</i></p> <p data-bbox="574 730 1443 842"><i>"And if they [patients] want to just sit there and try and work it out by themselves, then great – maybe that's their personality...I think you need to tell people what works for you." (P4)</i></p> <p data-bbox="574 856 1414 968"><i>"And she [P2] says, '...so if you can go a bit slow that would be nicer. I may seem fine on the outside, but on the inside my mind is trying to keep up with you.'" (C2)</i></p> <p data-bbox="574 982 1393 1121"><i>"If I don't understand something that he says, I'm just going to say, "What was that? Can you phrase that in a different way, or can you write it down? Or, can we go over this again? I don't know what you're saying." (P4)</i></p> <p data-bbox="574 1136 1354 1247"><i>MB: "Okay, so if you were this person...and you couldn't communicate, would you still want to be part of the decision-making process?"</i></p> <p data-bbox="574 1247 818 1281"><i>P3: "Yes. If I can."</i></p> <p data-bbox="574 1295 1443 1407"><i>"No, but he wants to be informed. To be informed is very important to him. I suppose some patients just want to be taken care of and made well and pampered and whatever." (C5)</i></p> <p data-bbox="574 1421 1377 1488"><i>"Well, I guess the thing...as much as I can for me, try to do it." (P3)</i></p> <p data-bbox="574 1503 1349 1537"><i>"If something I feel very strongly about, I will ask him." (P2)</i></p> <p data-bbox="574 1551 1377 1663"><i>MB: So, as the patient, you're trying first to communicate. If it doesn't work, then have the caregiver try and help you ... (P5 nods). (P5)</i></p> <p data-bbox="574 1677 1382 1745"><i>"I can't give them...what it's, what...the research is on it. But I can tell them how it has affected me." (P4)</i></p> <p data-bbox="574 1759 1443 1829"><i>"If he [doctor] asks you something, be as honest as you can. That's the only way that he's going to be able to do his job." (P4)</i></p>

Signals caregiver to jump in.

"And P3 is the one who can give me the cue that it's time for me to jump in, and either clarify what the doc is having to say or clarify P3's response or respond if he can't come up with the answer." (C3)

"If he feels like he's not getting through, or can't completely answer a question that's been asked, he will turn to me and let me know that it's my turn to jump in." (C3)

"Sometimes she'll look at me and kind of, you know say, "Hey" or give me a look like, "Hey, can you answer this for me?" (C6)

"If you see her trying to say something, then I try not to fill-in. If she looks at me like, "What should I say?" then I will fill-in." (C1)

"...she'll look to me if she can't quite get it...or explain it." (P1,C1)

Monitors the accuracy of the conversation.

"...she will even correct me sometimes if, if it's not quite what I...what she wanted to say." (C1)

"I'll try and ask a question the way I think she wants it. If that doesn't work, I'll look at her and she says, "No. That's not it." (C2)

"And if I'm saying it wrong, she'll say, "No. That's not it." (C1)

APPENDIX R: SUMMARY OF PATIENTS' COMMUNICATION STRATEGIES

Summary of Patients' Communication Strategies

General Communication Strategies

Try speaking to physician directly (not through caregiver)
Let physician know what communication strategies work at beginning of medical interaction
Disclose aphasia diagnosis at start of medical interaction
Have caregiver speak for patient/help with communication when patient struggles

Specific Communication Strategies (Expressive)

Use gestures and pointing to supplement verbal communication
Signal caregiver to help with communication
Speak slowly to caregiver and physician
Use facial expressions to supplement communication
Use writing and drawing to supplement or replace speech
Use AAC device (i.e. Lingraphica, Proloquo to Go) to supplement verbal communication
Check for understanding after speaking
Give up if message not crucial
Verbalize key word(s) to help others with understanding topic of conversation

Specific Communication Strategies (Receptive)

Ask for repetition or clarification of questions and information
Request additional time to process information/think
State when information not understood
Monitor conversation between caregiver and physician and correct information as needed
Tell people to say "one thing at a time"
Tell physician to slow down when speaking

Strategies Outside Medical Interaction

Meet with caregiver prior to medical interaction to discuss what to say and ask during interaction
Review information with caregiver for recall after medical interaction
Use calendar on phone to keep track of appointments

APPENDIX S: ROLE OF CAREGIVERS

Role of Caregivers

<u>Role Description</u>	<u>Participant Quotes</u>
Advocates for/supports the patient.	<p data-bbox="610 457 1438 527"><i>"You [C2] know my likes and dislikes. I can't articulate them to you, or to the doctor, so you're my voice now." (P2)</i></p> <p data-bbox="610 541 1029 575"><i>"Protector of the message." (C5)</i></p> <p data-bbox="610 590 1438 659"><i>"And protector...of his answers to make sure that the doctor, or whoever he's talking to, gets the correct answer." (C5)</i></p> <p data-bbox="610 674 1357 743"><i>"'Cause they're the ones who will have the challenge. You don't. So, you gotta help them through the process." (C2)</i></p> <p data-bbox="610 758 1321 791"><i>"When you're there [C2], I can just speak freely." (P2)</i></p> <p data-bbox="610 806 1045 840"><i>"I'll be there as a safety net." (C2)</i></p> <p data-bbox="610 854 1357 924"><i>"That you make sure that you're giving...that C4 would be giving me as much authority as...as she would want." (P4)</i></p> <p data-bbox="610 938 1403 1052"><i>"Okay, I want you to...you know...this is, this is you getting better. I can't do it for you. You have to do it yourself, but I'm there." (C2)</i></p>
Interprets for the patient.	<p data-bbox="610 1079 1438 1220"><i>"When you're talking about independence, you need to let this person with a communication disorder try everything they possibly can before you jump in and become the translator." (C3)</i></p> <p data-bbox="610 1234 1438 1304"><i>"If I weren't there, they might not know like some key important things about her." (C6)</i></p> <p data-bbox="610 1318 1370 1388"><i>"And, um...so I try and simplify it, you know so it's easier." (C2)</i></p> <p data-bbox="610 1402 1438 1472"><i>"To make sure that he gets...like I said to interpret the message if it's something I don't think he understands." (C5)</i></p> <p data-bbox="610 1486 1438 1598"><i>"Uh, interpreter. You know, if it gets too technical or too fast for him...then I will try to slow it down or simplify it, or explain it compared to something he's familiar with." (C5)</i></p>
Monitors and facilitates the conversation.	<p data-bbox="610 1625 1438 1841"><i>"I let them talk or whatever, but I'm kind of there to like "steer the ship" sometimes. You know, because it's important for her [P6] to talk. But, if there's anything that she's having a block with and I know what she's talking about, or if the doctor asks like a really specific question I know it would be tough for her to answer, then I'll fill in that information." (C6)</i></p> <p data-bbox="610 1856 1438 1890"><i>"And so, and sometimes you let the person... (points to P4)...um,</i></p>

Monitors and facilitate the conversation (cont.)

express themselves and sometimes you just make it...go smoother." (C4)

"Out of sight as much as possible." (C4)

The "guide on the side" during medical appointments. (P3-C3)

"I've tried to stay back and... 'cause it's not my you know, appointment or whatever." (C6)

"I know that you're making an effort. I know you have ways that you think will work. And I need to respect that until you tell me that you need my help." (C3)

"And in my caregiver training, you have to let the adult be independent...if that's what they...you know, you can't keep them prisoner." (C1)

"So, I had to learn where I could fit with her. But, also understood that she wanted to be independent." (C2)

APPENDIX T: SUMMARY OF CAREGIVERS' COMMUNICATION STRATEGIES

Summary of Caregivers' Communication Strategies

General Communication Strategies

Let physician know what patient can/cannot do at start of medical interaction
Ask physician to repeat if needed
Direct physician to communicate with patient
Clarify information for the patient
Provide basic medical information so patient can focus on current visit
Wait/stay quiet until patient struggles, then help with communication
Listen to the patient
Anticipate patient's needs when necessary
Speak for the patient if patient unable or strategies do not work
Wait/stay quiet until physician struggles to understand, then help with communication
Demonstrate communication strategies for physician

Specific Communication Strategies

Simplify information presented to patient
Slow down information presented to patient
Provide choices to patient
Repeat information for patient
Check for patient understanding
Draw information to help patient understand
Give patient time to respond
Let patient know when something is not understood
Ask patient for clarification
Fill in key word/information for patient to help keep communication going
Double-check patient's answer to ensure it is what was intended
Ask patient to give key words for context
Write down information for patient to refer to during medical interaction
Write down information to go over with patient after medical interaction

Communication Strategies Outside of the Medical Interaction

Learn about patient's communication disorder (get educated)
Use email to communicate with physician outside of face-to-face medical interaction
Email/call ahead of time to provide information about patient and reason for medical interaction
Review information from medical interaction with patient at home after interaction
Attend speech therapy sessions to learn how to communicate better with patient
Write out steps for patient to follow for accomplishing tasks

APPENDIX U: ADVICE TO PHYSICIANS

Advice to Physicians

<u>Advice Description</u>	<u>Participant Quotes</u>
Respect the patient.	<p><i>"Respect the whole. Whatever that whole is." (P4)</i></p> <p><i>"Respect the fact that he wanted to do some learning around this whole issue, not just his specifics." (C3)</i></p> <p><i>"And, for the doctors to not high-brow the patients. You know, to make them feel that they're...well you know, 'You're just the patient. I'm the doctor. I know it all.'" (C5)</i></p> <p><i>"And it doesn't need to be much. Just 1 or 2 comments can break the ice and make things more comfortable for the person with aphasia who is uncomfortable in the beginning because they know they can't find the right words." (C1)</i></p> <p><i>"And don't forget, just because they can't speak that they don't think...and have an opinion. And have a brain that's working...it might be a little slower to totally encompass the issue, but the brain is still functioning." (C5)</i></p> <p><i>"...she's still intellectually smart, even though she doesn't look like it or sound like it." (P6)</i></p> <p><i>I think a lot of people immediately jump to the conclusion when they hear people with speech issues, that somehow there's a cognitive deficit there too...you know, just cause they can't get the words out doesn't mean that the words aren't in there." (C3)</i></p> <p><i>"Don't let the wheelchair take away the brain power." (C5)</i></p> <p><i>"...if the person that you're listening to doesn't have faith in you or doesn't believe that you...or he's something special, then they're probably not going to open up to you." (P4)</i></p> <p><i>"And that's going to be a very important thing for the doctor...to be patient." (C1)</i></p>
Talk directly to the patient.	<p><i>"You're the patient. Your appointment. They should start with the patient, look them in the eye, and ask them what the issue is." (C5)</i></p> <p><i>"But I think that being there and in person...actually being affected like as a person is like way more important than just getting the information in general." (C6)</i></p> <p><i>"Well, it's not like they don't talk necessarily to him, but they direct the questions to me. Um, if that happens, I immediately say, 'P4, you answer that.' And then if he stumbles, I'll step in, but it still has to start with him." (C4)</i></p>
Talk directly to the patient (cont.)	<p><i>"Cause they [patients] don't like to be talked about in the 3rd person." (C1)</i></p>

Try to understand what patients with communication disorders are going through.

"It's very important that regardless of what... (points to herself) ...the back-up person...the data we can give, whether it be the numbers or the spelling, or whatever... (points to P4) ...that they keep looking at him. And ignore me." (C4)

"...wants the doctor to look at him [P5]. Not the doctor talking to me... (points to P5) ...and he's the patient." (C5)

"Sometimes people will start looking at me for the answers, but they should...I think...that he's...he [P4] needs to be addressed, and then I'll just silently...I'll just quietly... (points multiple times to P4) ...give the information." (C4)

"You should be able to...when you look at somebody who's having a really tough time, you should feel for them. You should know that there's something more behind it than them just having a problem. Like when you leave, they're still dealing with it 24 hours a day." (C6)

"There's like the knowledge of the feeling of the individual...like 1-on-1 individual feeling of like being able to know that like not only does this problem suck, and it's tough to communicate with, but that the person who you're talking to is struggling twice as hard as you are to get the information out than you are trying to receive it." (C6)

"Be patient. Get yourself educated about aphasia. And then learn...understand what the person you are looking after what they can do and cannot do. And they can't tell you. You have to watch." (C2)

"Part of being a doctor is communicating with your patients, and if you're willing to go out there and learn about their problems and actually meet people with the problem, then I think that'd probably be a doctor I'd want to see." (C6)

"One thing I realized is when you write things down, It really like slows down how you speak. And it does help a lot. And I feel like doctors obviously shouldn't be doing that with everybody, but I think that they should at least know." (C6)

"Well, it would be lovely if a physician were sensitive enough to the situation to have that [pencil and paper; wipe board] available. Absolutely. And I think that would convey to the patient some compassion and some understanding of their situation, which I think is huge." (C3)

Try to understand what patients with communication disorders are going through (cont.)

"Cause we have concerns. And those are rightful concerns whether we read the wrong thing or not, that's a different thing. We have concerns. Because going to a doctor, and they open the hood, something's not going to look good...and...and just suggesting a...uh, uh...diagnosis, saying you know, "You need to do this" is not enough for us." (C2)

- "Well, I'll get better... (nodding)...I will." [Let patient know that] (P6)*
- Be willing to take the time and learn how the patient communicates.
- "...you know that when you hear it...this doctor is in a real rush. He wants to see all his patients, and they, they are good doctors, but not good for me...because I am...even without a stroke, I am...I would like them to explain just a little bit better." (P2)*
- "I think a lot of it has to do with just taking the time..being willing to just sit and listen, and try to figure out what's going on." (C3)*
- "I think the primary message that I would want to give to physicians is plan on the time. Plan on the time. Knowing that you have an aphasic patient." (P3)*
- "extremely generous with his time" (C5)*
- "I realized it takes more time to communicate. It just does, and I think hopefully physicians are willing to be aware of that...plan that in." (C3)*
- "if you're dealing with people like me, or like anybody who has any disorder...um, it's important to know what that disorder is, and maybe even if it's the first time, maybe even try and see if anyone else has even dealt with something like this before..." (P4)*
- "And I was kind of hoping he would make that jump and just try to communicate..." (C3)*
- "He [MD] just seems genuinely concerned. And he just slows down...and he comes right up, and just has that wonderful manner that...that works." (C4)*
- Be prepared to try different communication strategies.
- "You know, if they ask him a question that's yes or no, frequently they'll come up with the wrong answer first. And then they'll realize they're wrong and come back. But if the person who is doing the interviewing keeps on and doesn't wait for this correction, then all the information is messed up." (C5)*
- "And you know, it takes more than twice as much time to deal with someone who has a communication difficulty, so you need to really account for that." (D4)*
- P5: "Talk."*
- MB: "How?"*
- P5: "Slowly."*
- "I mean, it's not rocket science. But having them think, 'Oh yeah. I should just pull out a piece of paper and draw this, or...'" (C2)*
- Be prepared to try different communication strategies (Cont).
- "And I think she's saying that if the doctor like took a course on that or something, they might be able to speak better with someone with aphasia." (C6)*
- "Be patient because often time there's a response coming, you just need to wait for it." (D4)*

"Well, I think for me more. More time to do it." (P3)

"And being aware that there will be other modalities of communication besides just talking. And you know, maybe even providing for that. Making sure that in the exam room there's a pencil and paper." (C3)

"So fast...too much...and then slow...it...down." (P1)

"Think, think...I'm sure, same thing. Jus...slow down." (P1)

"I think the biggest thing is being willing to give it time." (C3)

"But I guess the other thing for me would be that, to have the doctor doing some scribing, doing some writing because there are some things that you can read if he's trying to communicate with you...that you might understand better if you read them, than if you're listening to him talk to you about it." (C3)

"...so I think that's really important for a doctor to be able to say to someone, 'If you're not getting it, not just repeat it and repeat it. But say, 'Oh. Yeah. How can I...okay, how about this?'" (P4)

APPENDIX V: SUMMARY OF PHYSICIANS' COMMUNICATION STRATEGIES

Summary of Physicians' Communication Strategies

General Communication Strategies

Have SLP help with communication

Ask patient and caregiver how best to communicate with patient

Become familiar with patient and his/her condition and communication disorder

Write information down for patient to take home for review after medical interaction

Check for patient and caregiver understanding

Allow sufficient time for medical interaction to occur

Specific Communication Strategies

Look at patient/address patient directly

Use AAC device, or communication board

Use less open-ended questions based on patient's communication abilities

Use vocabulary patient will understand

Use pictures/drawings to supplement communication

Write down information for patient to refer to during medical interaction

Ask caregiver to clarify if information not understood by patient or physician

Slow down pace of conversation

Give patient time to respond

Ask yes/no questions

Use visual cues

Look to caregiver to verify/refute information

Simplify information/use simple language